

**WOMEN'S EXPERIENCES OF BREAST CANCER:  
A LONGITUDINAL PERSPECTIVE**

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## **ABSTRACT**

Utilising a hermeneutic phenomenological approach twenty women's experiences of breast cancer were explored through semi-structured interviews at three time points during their healthcare trajectory from recent diagnosis to early follow-up. Phenomenological analysis guided by van Manen's (1990) principles revealed numerous multifaceted themes some of which were time limited while others spanned the data collection period. Use was made of an adapted life grid approach in order to enhance the implicit meanings to be elicited through interpretation of text. Central themes depicting the medicalisation of breast cancer, perceptions and management of the body and participants' emotional journey were uncovered.

Breast cancer was found to represent a biographical disruption that had a long-term impact on a woman's body, self, identity and sense of embodiment. Changes to the body, due to breast cancer treatment, and an altered way of being in the world, elicited disruption to the body-self relationship, a separation that was reinforced by the healthcare system. Participants were found to adopt a variety of coping strategies to manage ongoing change and the stress elicited by experiencing breast cancer as a chronic illness. Avoidance, information management, conscious passivity in treatment decision-making and positive cognitive restructuring are examples of such mechanisms. However, women's experiences of each theme identified and the emergence and maintenance of these themes varied according to women's biography, diagnosis and prescribed treatment regime, cancer schema, and social support. Accordingly, models of care must address women's individual experiences and recognise their changing needs throughout the year post diagnosis.

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## **ABBREVIATIONS**

|           |   |
|-----------|---|
| BSE       | Breast Self-Examination                             |
| CSM       | Common-Sense Model                                  |
| DCIS      | Ductal Carcinoma In Situ                            |
| DIEP Flap | Deep Inferior Epigastric Perforator Flap            |
| ER        | Oestrogen Receptor                                  |
| FNA       | Fine Needle Aspiration                              |
| GP        | General Practitioner                                |
| HER2      | Human Epidermal Growth Factor Receptor 2            |
| HRT       | Hormone Replacement Therapy                         |
| LD        | Latissimus Dorsi                                    |
| NHS       | National Health Service                             |
| NICE      | National Institute for Health & Clinical Excellence |
| SLN       | Sentinel Lymph Nodes                                |
| SLNB      | Sentinel Lymph Node Biopsy                          |
| STA       | Strategic Health Authority                          |
| UK        | United Kingdom                                      |



## OVERVIEW OF THE THESIS

This thesis reports an exploration of women's experiences of breast cancer throughout the healthcare trajectory from shortly after diagnosis to early follow-up, one year later.

Chapter 1, 'Biomedical Perspectives on Breast Cancer', provides the reader with contextual and background information regarding breast cancer, describing the existing medical knowledge on the disease including incidence and risk factors. Current debates regarding screening for breast cancer are illustrated with consideration of the effectiveness of breast self-examination and mammography. The healthcare trajectory from identification to diagnosis, treatment and follow-up is reviewed as is the contradictory research base pertaining to breast cancer treatment decision-making. The chapter concludes by documenting the view of breast cancer as a chronic rather than acute illness and the associated issues of survivorship.

Chapter 2 entitled 'The Illness Experience of Breast Cancer: Self, Identity, Body and Embodiment' provides an overview of self and identity theory from both psychological and sociological standpoints. The notion of embodiment is described and the relationship between the mind and body in times of illness is discussed. The ways in which the medical profession can reinforce a mind-body separation, with specific reference to breast cancer and Frank's (1995) conceptualisation of problems of embodiment and typologies of body-self are reviewed. Drawing on a variety of perspectives the meaning of women's breasts and the associated impact on women's sense of self and identity following breast surgery are explored. The controversy surrounding women's use of

reconstruction and prostheses to maintain a 'normal' bodily appearance is also highlighted. Finally, existing empirical research is evaluated with a focus on qualitative and longitudinal studies of cancer patients' experiences in relation to self, identity and embodiment.

Physiological and psychological theories of stress and coping form the first part of Chapter 3 'Stress and Coping with the Breast Cancer Experience'. This chapter provides an overview of the most commonly reported coping strategies in the breast cancer literature and documents the most influential theories of social support and its impact on coping with cancer. Given the vast quantity of research concerning women's psychological well-being following a breast cancer diagnosis, the most prominent works in the field are appraised with particular attention to the impact on quality of life and the development of psychological morbidities. The notion of control and its relationship with breast cancer and psychological well-being is investigated.

Chapter 4 describes the study methodology incorporating a history of the emergence of hermeneutic phenomenology and its suitability for exploring women's longitudinal experiences of breast cancer. The development and use of illness/treatment grids to aid the data collection process as based on a life grid approach is discussed and an overview of participant characteristics is provided.

Chapters 5, 6, and 7 constitute the 'data' chapters and represent the so-called 'parts' of women's experiences as outlined in Heidegger's hermeneutic phenomenological approach (e.g. Heidegger, 1927/1996). Given the multitude and diversity of themes identified the extant literature is applied to the study findings throughout the data chapters.

Chapter 5 'The Medicalisation of Breast Cancer' reports women's interactions with the healthcare system and the issue of waiting from symptom identification to early follow-up. The themes presented demonstrate how women's lives became medicalised through diagnostic and treatment regimes resulting in a wait for normality and desire to return to their former self. Women's roles with regards to treatment decision-making and the influence of historical context, acceptance of medical opinions, and women's pursuit of survival, in this process are revealed. Women's cancer schemas are described including perceptions of aetiology and the implications of these beliefs on psychological adjustment and help-seeking behaviour. Coping strategies pertaining to the management of information throughout the year post diagnosis are uncovered as is women's struggle to regain responsibility for their breast health. Finally, this chapter reports findings indicative of an ongoing reliance on the medical profession and the consequence for breast self-examination throughout the healthcare trajectory.

Chapter 6, 'The Body', is divided into three parts, the first of which presents themes pertaining to women's perceptions of the body. This section demonstrates how through rationalising breast surgery the meanings women ascribed to their breasts were revealed. It additionally outlines women's perceptions of breast loss from immediately post-surgery and highlights the impact on women's identity and notions of self. The bodily limitations that women experienced as a result of breast cancer treatment are discussed in relation to a loss of healthy identity and lack of embodiment. The second part of this chapter focuses on women's body management and the strategies adopted to cope with the changed body including women's use and non-use of external breast prostheses and reconstructive surgery. It is argued that women's

attempts to re-image the body through clothing and disguising chemotherapy-induced alopecia are related to stigma, body regulation and societal control. Women's experiences of complementary therapies are considered as a means of managing treatment side-effects. The final section and theme contends that women's perceptions of their body and ongoing management of appearances act as permanent reminders of bodily change.

The themes that represent women's emotional journey are presented in Chapter 7 'The Mind'. Drawing on models of grief this chapter charts women's psychological responses and adjustment to breast cancer throughout the year post diagnosis commencing with acute stress reactions. Women's attempts to protect others and their self-concept are discussed and their search for meaning and reflection on existential concerns regarding mortality are demonstrated with reference to associated coping strategies. The psychosocial distress that frequently emerged following a period of reflection is reviewed and qualitative accounts of depression and loss of personality are presented. Literature from positive psychology is applied to women's use of positivity and the notion of biographical disruption is used to conceptualise women's altered frame of reference. The changes women made to their lives as a direct result of experiencing breast cancer are reported ranging from health-related behaviour change to re-defining life priorities and reforming relationships. The final theme presented portrays the untidy ends that remain a core component of women's experiences of breast cancer over time revealing the impact of uncertainty and the challenge of moving beyond breast cancer.

Chapter 8, 'Discussion', considers women's experiences as a 'whole' and contextualises the study results in light of self, embodiment and coping theory

as well as reviewing implications for current healthcare policy. Reflection on the research methodology, study limitations and directions for future research are discussed.

# **CHAPTER 1: BIOMEDICAL PERSPECTIVES ON BREAST CANCER**

## **1.1 Introduction**

This chapter reviews biomedical perspectives on breast cancer beginning with prevalence and the biology of the disease with the aim of providing contextual information regarding the dominant objectivist model of breast cancer care in the UK. It charts the healthcare trajectory from identification to treatment pathways and follow-up and provides an overview of the contested area of decision-making in this context. Risk and the increasing acknowledgment of breast cancer as a chronic illness are additionally considered. The chapter draws on UK Government reports that are currently influencing practice and documents produced by cancer charities alongside empirical research to highlight the continuing magnitude of the disease as well as current debates in the field. In turn, the need for further research into breast cancer and specifically that exploring the illness experience from a longitudinal perspective and constructivist philosophy is outlined.

## **1.2 Prevalence**

The past three decades has seen the incidence of breast cancer increase in many parts of the world and the disease remains the most common female cancer in developed countries (Jemal, Siegel, Xu & Ward, 2010). In 2009 40,260 new cases of breast cancer were diagnosed in England, with more than 99% of cases being diagnosed in women (Office for National Statistics, 2011). Accounting for 32% of cancers in women in the UK (Clinical Knowledge Summaries, 2009) with a lifetime prevalence rate of one in eight for women,

breast cancer has become the most common cancer in women in the UK. On a global scale it is estimated that 1.38 million women were diagnosed worldwide in 2008 accounting for nearly a quarter of all female cancer cases (Ferlay, Parkin & Steliarova-Foucher, 2010). Incidence rates vary across the globe with the highest rates being found in Europe while the lowest rates have been observed in Africa and Asia (Ferlay et al., 2010). Variation in the incidence of breast cancer is also observed across the UK. The North East of England is reported to have the third highest proportion (11%) of breast cancer cases in England with only the Thames and South West regions reporting a greater incidence of the disease (West Midlands Cancer Intelligence Unit, 2011). Higher rates of diagnosis have consistently been reported in the least deprived populations of the UK such as those in the South West however, the North East reports one of the greatest percentages of breast cancer cases in the most deprived quintile (West Midlands Cancer Intelligence Unit, 2011).

In line with having one of the highest incidences of breast cancer in the world 12,047 women and 69 men died from breast cancer in the UK in 2008 (Cancer Research UK, 2011a). Data suggests that 5% of women diagnosed with breast cancer at the time of diagnosis had metastases (NICE, 2009). That said, survival rates are over 80% and the latest available statistics suggests that on 31<sup>st</sup> December 2006 approximately 298,000 individuals were alive ten years after receiving a breast cancer diagnosis, 99% of whom were women (National Cancer Intelligence Network, 2010). However, 35% of patients develop metastases in the ten years following diagnosis (NICE, 2009) and at least one third of patients develop recurrent disease (NICE, 2002).

Deaths from breast cancer have been reported to be decreasing in North America, Australia and the majority of Nordic and Western European countries (Autier et al., 2010) yet breast cancer survival rates in England continue to remain lower than those in the best performing countries (Coleman et al., 2011). Variation in the stage of breast cancer at diagnosis and differences in breast cancer treatment are believed to be influential in explaining European variation in breast cancer mortality rates (e.g. Allemani et al., 2010; Sant et al., 2003). A large scale investigation of hospital reports found that women in the UK were diagnosed at a later stage, were operated on less often, had fewer nodes sampled, and had a lower rate of axillary dissection compared to women in other European countries (Sant et al., 2003).

Delayed presentation to a GP has been suggested as one explanation for the diagnosis of UK women at a more advanced stage of breast cancer (Coleman et al., 2011) and a link between such delay and survival is apparent (Richards, Westcombe, Love, Littlejohns & Ramirez, 1999). Delay in help-seeking for a breast symptom has been found to be associated with older age, non-recognition of symptom seriousness, and lower education level (Macleod, Mitchell, Burgess, Macdonald & Ramirez, 2009). Moreover, a recent study has found that 37% of women surveyed in the UK stated that they might not seek advice from their GP due to worry that they would be wasting the doctors' time (Forbes, Atkins, Thurnham, Layburn, Haste & Ramirez, 2011). Fear of what the doctor might find, embarrassment and a lack of confidence in talking about their symptoms were also among the most prevalent barriers to help-seeking identified by Forbes et al. (2011). Socio-cultural factors may also play a role in such delays particularly regarding the meanings ascribed to breasts. Symbolic associations with maternity and the relationship between beauty and health



have been reported to constitute explanations for delay in a sample of women in the USA (Potrata, 2011). This issue aside, mortality rates should be interpreted with caution as they provide a delayed picture of survival trends given that a substantial proportion of women will have been diagnosed several years prior to death (Coleman et al., 2011).

Reported projections regarding the future incidence of breast cancer in England are mixed as while some studies predict an increase amounting to approximately 1% annually to 2020 (Møller et al., 2007) others argue that age-standardised incidence of breast cancer in the UK will decline by 8% between 2007 and 2030 (Mistry, Parkin, Ahmad & Sasieni, 2011). Such differences may be accounted for by recent changes to breast cancer screening and a substantial decrease in the use of Hormone Replacement Therapy (Parkin, 2009). Nonetheless, predictions to 2022 indicate a rise in the number of cases of breast cancer in the North East of England due to increases in both risk and population (Northern & Yorkshire Cancer Registry and Information Service, 2008).

The high prevalence of breast cancer in women and in the North East of England provides the foundation for the sample recruited for the present study. Accordingly, unless otherwise stated, the discussions within this thesis are restricted to female breast cancer. The following section describes the biology of the disease including the staging systems currently in use to aid treatment planning in the symptomatic breast unit from which the study sample was drawn.

### **1.3 What is breast cancer?**

Cell growth and division is a necessary function of the body in order that growth and repair of body tissues can take place. However, when the cells that make up the breast tissue fail to die and instead endlessly divide breast cancer is the result. This uncontrolled growth produces tumours known as neoplasms. These primary tumours may or may not be felt or seen in the form of a breast lump or other deformations of the breast (e.g. leaking nipple, skin dimpling, change in skin colour or texture) (Breast Cancer Care, 2010). While breast cancer begins in breast tissue it can spread to nearby tissues or organs as well as to other parts of the body. If breast cancer is isolated within the breast or is located in the breast tissue and the nearby lymph nodes and has not spread to other parts of the body it is termed 'early' (NICE, 2009). 'Locally advanced' is the term used to describe breast cancer that may be identified within a large part of the breast, may be growing into the skin or muscle of the chest and may be present in the lymph nodes though has not spread to other body parts. 'Advanced' breast cancer is diagnosed when cancer has spread to other parts of the body or when its growth into nearby tissues cannot be fully removed via surgical intervention (NICE, 2009).

Breast cancer is further defined in terms of type, being described as either non-invasive or invasive (NICE, 2009). Non-invasive breast cancer, also known as carcinoma in situ, is found in the milk ducts with no evidence of spread to the surrounding breast tissue (NICE, 2009). The most common form, known as ductal carcinoma in situ (DCIS) (Department of Health, 2010), is a lesion that during the early 1980s was reported as being relatively uncommon and was associated with patients presenting with palpable tumours and severe nipple discharges (Skinner & Silverstein, 2001). However, advances in mammography

technology and greater use of mammography screening has resulted in a rapid increase in the incidence of DCIS and accordingly women typically present as asymptomatic with nonpalpable tumours (Skinner & Silverstein, 2001). While if left untreated DCIS can develop into invasive breast cancer, it has been estimated that two thirds of such cases will not progress into invasive tumours (Page, Dupont, Rogers, Jensen & Schuyler, 1995). Consequently, issues regarding the overdiagnosis of DCIS due to publicly organised mammography screening (J0rgensen & G0tzsche, 2009) and debate as to whether DCIS should be treated like early stage invasive breast cancer has arisen (Allegra et al., 2010). Furthermore, many believe that the anxiety-inducing term 'carcinoma' should be removed from diagnosis (Allegra et al., 2010). Nevertheless, there is no definitive way of determining whether a DCIS of the breast will remain encapsulated or become invasive (Zahl, Maehlen & Welch, 2008). As evidenced via several women in the sample recruited for the present study, DCIS of the breast was diagnosed via a symptomatic breast unit and treated as breast cancer by both women and healthcare professionals.

In contrast, invasive breast cancer is characterised by spread or 'invasion' into the surrounding breast tissue. This type of breast cancer has the ability to spread into tissue outside of the breast. Invasive ductal breast cancer is the most common form of breast cancer, developing in the cells that line the breast ducts, accounting for approximately 80% of all breast cancers (Department of Health, 2010). When breast cancer spreads to other parts of the body, usually via the lymph nodes or the bloodstream, it is known as secondary or metastatic breast cancer (National Cancer Institute, 2011).

When breast cancer is diagnosed it is given a stage describing the size of the cancer and how far it has spread (Breakthrough Breast Cancer, 2009). One staging system often utilised in breast cancer diagnosis is the TNM system (Macmillan Cancer Support, 2011). This can provide detailed information about the extent of the cancer by describing the size of the tumour (T), whether cancer has spread to the lymph nodes (N) and whether cancer has spread to another part of the body - metastases (M) (Benson, 2003). While this staging system has been applied in oncology for over fifty years its usefulness is now in question (Mason, 2006). Burke (2004) argues that in order to provide individualised care that can guide treatment decisions a new system incorporating newly discovered biomarkers is needed. He further purports that routine screening that can detect cancer at earlier stages and the influence of treatments other than surgery are not accounted for in the TNM staging system leading to inaccurate predictions of prognosis (Burke, 2004). Accordingly, this may be pertinent to breast cancer care particularly given developments in knowledge of biomarkers including the role of oestrogen and progesterone positive and negative markers. Nevertheless, others oppose abandoning this framework and are working to improve the existing system believing that prognostic markers could be used in addition to the TNM system (Gospodarowicz, Miller, Groome, Greene, Logan & Sobin, 2004).

The number system of staging may also be used which categorises breast cancer from stage 0 to stage 4 (Cancer Research UK, 2011b) with non-invasive cancer such as DCIS being classified as stage 0 (Department of Health, 2010). Subsequent stages are defined by the location of breast cancer cells (e.g. in the breast, lymph nodes, elsewhere in the body) and/or the size of the tumour (in centimetres). More advanced stages such as stage 3 indicate that cancer cells

are stuck together or to other structures such as the skin or chest wall. A diagnosis of stage 4 breast cancer describes a tumour of any size and that the cancer has spread elsewhere in the body (metastasis).

Cancer cells are also graded in terms of low, medium and high to indicate the speed of growth and likelihood of spread. As such low grade (G1) tumours although abnormal are slow growing and less likely to spread while high grade (G3) tumours can grow quickly and are more likely to spread (Department of Health, 2010). The exact causes of female breast cancer are currently unknown, though several risk factors have been identified and are reviewed in the following discussion.

#### **1.4 Risk**

Age is one such non-modifiable risk factor with increasing age being linked to a greater likelihood of developing breast cancer (e.g. Cancer Research UK, 2009a; McPherson, Steel & Dixon, 2000). Eighty one percent of cases occur in women aged 50 years and over with nearly half of cases being diagnosed in women aged 50-69 years (Office for National Statistics, 2010). That said, breast cancer is the most commonly diagnosed cancer in women under 35 years (Cancer Research UK, 2009a).

As some breast cancer cells can be stimulated to grow with greater exposure to oestrogen, starting periods at a younger age, entering into menopause at a later age, not having children or doing so later in life may increase the risk of breast cancer by prolonging women's oestrogen exposure (Travis & Key, 2003). Being overweight or obese after the menopause causes greater production of

oestrogen and accordingly the risk of developing breast cancer is greater in this group of women (Travis & Key, 2003).

Socio-economic variations are evident with higher incidence rates of breast cancer being recorded in more affluent women. A recent comparison of two time periods, 1995-1999 and 2000-2004, reported that incidence in the most deprived groups in 2000-2004 were approximately 20% lower than in the most affluent (National Cancer Intelligence Network, 2008). Having a first pregnancy later in life and lower parity are more prevalent in women of higher socio-economic status. Similarly, an increase in the use of Hormone Replacement Therapy (HRT) has been documented as contributing to the increase in breast cancer cases seen during the 1990s (Beral, Banks, Reeves & Wallace, 1997), its use also being noted to be higher in more affluent women (Quinn, Cooper, Rachet, Mitry & Coleman, 2008). Berry and Ravdin (2007) estimate that due to the fall in the use of HRT (seen from 2001 onwards) there were 1,400 fewer cases of breast cancer in 2005 in women aged 50-59 in the UK than would have occurred without this decreased use.

While most breast cancers are not hereditary approximately 5-10% of breast cancers can be attributed to one of two predisposing genes, known as BRCA1 and BRCA2 (McPherson et al., 2000; Rahman & Stratton, 1998). Mutations in these genes relate to a lifetime risk of developing breast cancer of 50-85% and a 20-40% risk of developing ovarian cancer (Levy-Lahad & Friedman, 2007). The TP53 gene, the first tumour suppressor gene to be identified and the most common genetic change identified in human cancers, has also been associated with an increased risk of developing breast cancer (Gasco, Shami & Crook, 2002). The overall frequency of TP53 mutation in breast cancer is believed to

be approximately 20% (Pharoah, Day & Caldas, 1999). Women who have a significant family history of breast cancer i.e. the development of breast cancer in two close relatives such as a mother, sister, or daughter before the age of 50 years, may be eligible for genetic screening though a living relative with breast cancer is required for this procedure. Surveillance for breast cancer via annual MRI scans if less than 49 years of age and annual mammograms if over 50 years old should be offered if any of the relevant genes are identified (NICE, 2006).

Large scale studies have demonstrated that benign (non-cancerous) breast disease can additionally increase women's risk of developing breast cancer, in either the same or previously unaffected breast (Hartmann et al., 2005). Similarly, a previous diagnosis of breast cancer increases women's risk of developing the disease for a second time (Department of Health, 2010). Lifestyle factors including alcohol consumption, obesity, smoking and a lack of physical activity are not only risk factors for developing breast cancer but increase the risk of cancer recurrence (Kwan et al., 2010; McTiernan, Irwin & Vongruenigen, 2010) and the development of contralateral breast cancer (Li, Daling, Porter, Tang & Malone, 2009). Breastfeeding is known to have some preventative effects, a factor which relates to the production of oestrogen, though an exact link remains elusive (Collaborative Group on Hormonal Factors in Breast Cancer, 2002).

How women interpret their risk and how their perceptions affect screening behaviours and decision-making for preventive surgeries such as mastectomy is not completely understood (Pilarski, 2009). The complexity associated with this body of literature is represented by studies showing that objective breast

cancer risk factors are poor predictors of perceived breast cancer risk and screening behaviour (Katapodi, Dodd, Lee & Facione, 2009). Quantitative research studies tend to focus on women's assessment of their breast cancer risk. A cross-sectional community based survey undertaken in the USA with a multicultural sample of 184 women found that 50% of women perceived their breast cancer risk to be the same as the risk of their friends/peers (Katapodi, Dodd, Facione, Humphreys & Lee, 2010). Forty percent of women responders perceived their risk to be less than their friends/peers with only 10% of women perceiving that their risk was higher than their friends/peers. Family history and breast cancer worry were identified as significant predictors of risk judgments for the individual. Knowledge and salience of risk factors were found to inform comparative judgements. However, women's perceptions of their risk factors may not be accurate. Furthermore, the relatively small number of women with a family history of breast cancer and other risk factors limits the conclusions that can be drawn from the statistical analyses. Nonetheless, the study findings suggest that women may under-estimate or over-estimate their risk of breast cancer which may have implications for screening behaviours, use of health services and women's psychological well-being.

By contrast, a focus group study exploring psychosocial components influencing older women's breast cancer risk appraisal (Wood & Della-Monica, 2011) uncovered that worry, fear and anxiety were commonly expressed as women associated screening with a breast cancer diagnosis. 'Self-regulating empowerment' was the second theme discussed incorporating women's discourse on being proactive with their health, their engagement in health-promoting protective behaviours and information-seeking behaviours. The final theme, optimism, referred to how women perceived their life experiences as



enabling them to cope with the stress of receiving a breast cancer diagnosis should it occur. The use of a small, homogenous sample from a specific area of the USA provides a problem generalising the study findings to the UK. Furthermore, an issue relating to the misinterpretation of some of the focus group questions was acknowledged by the study authors. While older age is a non-modifiable risk factor and consequently this study explores an at risk population, risk perceptions may be different for women at different stages of their life.

The literature further suggests that the media representation of breast cancer and related risk factors in popular magazine articles portrays women not only as victims of an insidious disease but as victims of their behaviours (Lupton, 2004). The suggestion is that by, for example, delaying childbirth and using the contraceptive pill, women are making unhealthy or unnatural choices. Accordingly, women are seen to be increasing their risk of developing breast cancer, a disease that strikes a part of the body that is equated with being a woman. In taking more control over their lives by changing the prescribed roles and behaviours women are viewed as causing an epidemic and threatening the social order. The extent of this blaming has not been found to be the case in other press articles (e.g. Wilkes et al., 2001). While many women do recognise that there are risks over which they have no control there is evidence that women believe that the biggest cause of their breast cancer is childbearing and menopause (Wilkinson, 2000).

Inaccurate perceptions of breast cancer risk and risk factors may influence women's responses to the disease including health protective behaviours. However, given the strong association between endogenous risk factors and

the development of breast cancer, secondary prevention strategies are currently emphasised and promoted, by not only the UK Government and National Health Service but by the media. The following section considers screening with regards to both mammography and breast self-examination and highlights current debates in the effectiveness of these strategies.

## **1.5 Screening**

### ***1.5.1 Mammography***

Under national guidelines all women between the ages of 50 and 70 who are registered with a GP are currently offered regular routine breast screening via mammography (breast X-ray) with the aim of detecting breast cancer at an early stage (NHS, 2011). However, given the rolling nature of the programme inviting women from GP practices (or geographical areas) in three yearly cycles, some women will not attend screening until they are nearly 53 years of age. A randomised trial to extend this screening programme began in 2009 to include women from 47 years up to 73 years. The trial is due to be completed in 2016 though all women within this age range are anticipated to become eligible for mammography screening by the end of 2012 (NHS, 2011). Difficulties interpreting mammograms due to greater density breast tissue in younger women as well as the lower incidence of breast cancer in women less than 50 years of age constitute the reasons for the minimum age requirement. Despite women aged over 70 years having the highest rates of breast cancer in the UK (Office for National Statistics, 2010), after 73 years women cease to receive a routine appointment for mammography screening, though they can continue to request this via their GP. However, a recent study exploring the views of older women (over 70 years) towards mammographic screening reported that over

half (53%) of questionnaire respondents were unaware that they could request breast screening (Collins et al., 2010). Furthermore, most women (81.5%) had not attended breast screening since turning 70 years (Collins et al., 2010).

Approximately 1.88 million women were screened in the UK in 2010-11 via the National Breast Screening Programme representing growth of 45.1% from 2000-2001 (The Health and Social Care Information Centre, 2012). Expansion of the breast screening programme as detailed previously and population growth among women in the targeted age group are likely explanations for this increase (The Health and Social Care Information Centre, 2012). A participation rate of 70% is the national minimum standard (NHSBSP, 2005) in the UK and is an established goal within population health screening to ensure cost-effectiveness (Cosp, Castillejo, Vila, Marti & Emparanza, 2009). In 2010-11 uptake of mammography screening for routine invitations (women aged 50-70 years) was reported to be 73.4% (The Health and Social Care Information Centre, 2012). A variety of factors influencing participation have been reported in the literature including socioeconomic group, awareness of prevention programmes and the method of invitation (Cosp et al., 2009). While in the UK an effective active method of recruitment, as identified in a systematic review by Cosp and colleagues, by way of personalised letters of invitation is adopted, the percentage of eligible women attending screening varies across Strategic Health Authorities (STAs) in England. In the year 2010-2011 this ranged from 63.6% to 78.6% (The Health and Social Care Information Centre, 2012). Women who are not registered with a GP and who are not aware that they can request screening after 73 years are inevitably not considered in the reporting of such figures.

In women aged 50 to 70 years the detection rate in 2010-11 was 7.6 per 1000 women screened, a figure which has risen from those seen ten years ago given the introduction of two-view mammography in 2002 (The Health and Social Care Information Centre, 2012). The NHS breast screening programme conveys that an estimated 1400 lives are saved as a direct result of mammography each year in England (Department of Health, 2009) however recent systematic reviews have cast doubt on their effectiveness. Gøtzsche and Neilson (2006) reported that for every 2000 women invited for screening throughout a ten year period one will have her life prolonged while a further ten healthy women will be diagnosed with breast cancer and treated unnecessarily. This suggestion that some degree of overdiagnosis and overtreatment is an inevitable outcome of breast screening (Welch, 2004 as cited in Kusters & Gøtzsche, 2008) stems from the finding that several screen-detected cancers are slow growing and may not develop into invasive cancer if left untreated (Zahl, Maehlen & Welch, 2008). False-positive mammograms may, however, elicit an emotional impact and influence women's future screening behaviour. The results of a meta-analysis suggested that women who received false-positive results conducted more frequent breast self-examination, demonstrated variation in rates of subsequent mammography uptake and had higher levels of distress and anxiety and more thoughts of breast cancer than women who had received normal results (Brewer, Salz & Lillie, 2007).

Recently, a retrospective trend analysis of three country pairs comprising the Netherlands versus Belgium, Sweden versus Norway and Northern Ireland (the UK) versus the Republic of Ireland compared breast cancer mortality in relation to implementation of breast screening (Autier, Boniol, Gavin & Vatten, 2011). The countries in each pairing were similar with regards to healthcare services

and prevalence of risk factors for breast cancer death however mammography screening was implemented ten to fifteen years later in the second country in each pair. The study findings suggest that screening did not play a direct role in the decreasing mortality trends observed. Further to such findings an independent review of breast screening efficacy was announced in October 2011 to be conducted by The Department of Health in partnership with Cancer Research UK, with the results anticipated in 2012 (NHS Breast Screening Programme News, 2011).

### ***1.5.2 Breast self-examination***

Breast self-examination (BSE) refers to a woman being aware of the normal look and feel of her breasts and looking for changes including the size or shape of the breasts, skin texture, the presence of lumps, discharge from one or both nipples, swelling, redness and pain in the breasts or armpits (Breast Cancer Care, 2010). Women have long been taught that being breast aware can lead to an earlier diagnosis of breast cancer and in turn improve chances of survival (Kearney, 2006) and it has been documented that the majority of breast tumours are detected by women themselves (Arndt et al., 2002). However, this method of screening is also not without controversy.

A systematic review (Kosters & G0tzsche, 2008) identified two large population-based randomised trials assessing breast self-examination versus no breast self-examination. The first study, a collaboration between the Russian Federation and the World Health Organisation (Semiglazov et al, 1999), randomised women aged 40-64 years (excluding women with previous breast cancer or other malignancies) from St Petersburg and Moscow into a control or intervention group. Women in the intervention group who attended a routine

health check received a clinical breast examination, instruction in breast self-examination, and a follow-up calendar. However, discrepancies in published sample sizes, a lack of follow-up and non-reporting of study statistics from the Moscow site were noted limitations of this trial leading Kusters and G0tzsche to include only data from the St Petersburg site that was published in English. In the second study conducted in Shanghai (Thomas et al., 2002) 289,392 women aged 30-66 years were randomised into either an intervention group receiving education and reinforcement or to a control group. Kusters & G0tzsche assessed the Shanghai study as having a thorough training program including extensive instructions for breast self-examination, thorough follow-up procedures and higher compliance rates than the Russian study. No statistically significant differences in breast cancer mortality were identified between the intervention and control groups by either of these studies leading Kusters & G0tzsche (2008) to conclude that there was not a beneficial effect of breast self-examination. While in the Russian trial more cancers were found in the intervention group than the control group this was not the case in Shanghai which Kusters & G0tzsche suggest may be attributable to the lack of mammography available in Shanghai. Furthermore, as the trials showed that women who were randomised to the breast self-examination intervention were almost twice as likely to undergo a biopsy of the breast with benign results the authors suggest that BSE may lead to increased harm.

Meta-analyses of breast self-examination from the Canadian Task Force on Preventive Health Care (Baxter, 2001) and Hackshaw and Paul (2003) support the aforementioned findings and provide further evidence of harm as a result of increased medical visits, unnecessary biopsies and emotional distress (Baxter, 2001). The Shanghai trial in particular has been cited as responsible for

changing practice in a number of organisations (Kearney, 2006) and the Canadian Task Force on Preventive Health Care have gone so far as to recommend that doctors no longer teach BSE to women between 40 and 69 years of age during annual reviews.

However, a cohort study of nearly 30,000 women in Finland (Gastrin et al., 1994) and a Canadian case-control study (Harvey, Miller, Baines & Corey, 1997) reported findings suggesting that higher rates of breast self-examination were associated with decreased risk of mortality from breast cancer (relative to the general population). Gastrin and colleagues concluded that well performed breast self-examination in conjunction with a medical professional who was able to interpret women's findings was crucial in eliciting benefit from BSE. These studies do nevertheless lack the methodological rigour of randomised trials.

In summary, the effectiveness of breast screening whether via mammography or breast self-examination is a contested area. However, these methods do elicit diagnoses of breast cancer each year in the UK and represent a proportion of cases reviewed by the Symptomatic Breast Unit from which the current study sample is drawn. The following section outlines the healthcare trajectory from referral to possible treatment options.

## **1.6 The healthcare trajectory**

### ***1.6.1 Identification & diagnosis***

In line with the 2007 Cancer Reform Strategy all patients referred to a specialist breast clinic by their GP who are suspected of having breast cancer should be seen within two weeks. Symptoms may include a lump in a woman over 30 years of age that is not related to menstrual changes. Nipple changes such as

discharge, new nipple distortion and/or nipple eczema that is not present elsewhere and is not responsive to steroid treatment also warrant referral. Furthermore, symptoms including skin tethering, an area of the skin that has become fixed or eczema that as above is not relieved by steroid treatment constitute referral under the two week rule (NICE, 2005). Other symptoms that may result in referral include skin ulceration, a persistently recurring cyst, an abscess, pain which does not respond to initial treatment and one-sided lumpiness not associated with the woman's menstrual cycle (Breakthrough Breast Cancer, 2009). Women for whom abnormalities have been detected during routine mammography will automatically be sent for further assessment.

Upon referral to a specialist breast unit for investigation and potentially treatment women are reviewed by a multi-disciplinary team, a process which is now regarded as best practice (Association of Breast Surgery - BASO, 2009). The standard procedure upon attendance at a specialist clinic begins with a discussion regarding the breast symptoms being experienced and completion of a questionnaire including questions pertaining to family history of breast disease. This is followed by a breast examination by a nurse or doctor including the lymph glands in the armpits. A mammogram or ultrasound scan of the breast (for women under 35 years) may be subsequently undertaken, the results of which will determine whether a fine needle aspiration (FNA), whereby a sample of breast cells are removed using a fine needle and syringe, or core biopsy, using a larger needle to obtain a sample of breast tissue, is required (Breakthrough Breast Cancer 2009). Undergoing a clinical examination, radiological assessment and either a FNA or core biopsy is known as a triple assessment. At a one-stop clinic all testing is undertaken during their first visit to clinic and women receive the results of these investigations later that day.



Depending upon the hospital this may not be possible particularly if a core biopsy has been required and women may wait up to one week for their results (Macmillan Cancer Support, 2011).

The main treatments for breast cancer are surgery, chemotherapy, radiotherapy, hormone therapy and biological (targeted) therapy which may be used in isolation or combination. In the UK if locally or early advanced breast cancer is diagnosed surgery is the first method of treatment (NICE, 2009) and is the focus of the following sub-section.

### ***1.6.2 Primary surgical treatment***

The type of surgery undertaken is largely dependent upon the type of breast cancer identified (NICE, 2009). Breast conserving surgery, otherwise known as a lumpectomy or wide local excision, involves removal of the tumour and a small amount of surrounding breast tissue. A mastectomy is the term applied to the removal of the whole breast.

Noting that favourable outcomes were associated with less invasive surgery the concerns of a few influential surgeons that the standard use of radical mastectomy may constitute overtreatment led to a series of randomised controlled trials in the 1970s assessing the effectiveness of less invasive surgery (Lerner, 2001). A growing recognition that breast cancer warranted multimodal treatment added impetus to the decreasing popularity of aggressive surgery (Katz & Hawley, 2007). Several studies (e.g. Fisher et al., 2002) have since reported results of women followed-up for twenty years showing that for early stage breast cancer lumpectomy/breast conserving surgery yields comparable outcomes, in terms of local recurrence and survival, to modified

radical mastectomy. Moreover, better quality of life outcomes have been documented by several studies particularly regarding body image following breast conserving surgery as opposed to mastectomy (e.g. Janni et al., 2001). However, continuing high rates of mastectomy (e.g. Nattinger, Gottlieb, Hoffman, Walker & Goodwin, 1996) throughout the 1980s and 1990s have resulted in persistent concerns about the overtreatment of women by surgeons. The psychological impact of breast surgery is discussed further in Chapter 2 however the following sub-section reviews breast reconstruction and current guidance as to its use in the UK.

### ***1.6.3 Breast reconstruction***

While breast conservation has become the standard of care where possible (Fitzgal & Gnant, 2006) it is estimated that up to one third of breast cancer patients still require mastectomy (Cordeiro, 2008). NICE treatment guidelines (2009) state that where a mastectomy is necessary the healthcare team should discuss the possibility of reconstructing the breast during the mastectomy surgery, a procedure termed immediate reconstruction. This is not suitable for all women given the presence of other conditions or a need to wait until other treatments have been completed. Rates of mastectomy with immediate reconstruction vary across the UK with the North East of England having the lowest rate of this combined surgery (National Collaborating Centre for Cancer, 2009). Furthermore, when compared to other UK regions, the North East has the smallest rate of other excision (primarily lumpectomy) and the highest rate of mastectomy without reconstruction, and uniquely similar figures are reported for these two surgical interventions (National Collaborating Centre for Cancer, 2009).

If reconstruction is undertaken at a later date it is known as delayed. Delaying reconstruction until after the completion of adjuvant therapies was thought to be beneficial to prevent delays in the administration of chemotherapy (Heneghan et al., 2011). Moreover, radiotherapy has been found to compromise the viability of a reconstruction, impairing wound healing and leading to fat necrosis, capsular contracture and reduced cosmetic outcome (Chevray, 2008). Comparable quality of life scores have nevertheless been found in women who underwent immediate breast reconstruction and women who underwent breast conserving surgery (Heneghan et al., 2011). This Irish study utilised validated quality of life scales sensitive to breast cancer and a large cohort with 179 women completing assessment though a mean follow-up time of 36 months is relatively short. Reconstruction can involve the insertion of a breast implant or by using tissue from another part of the body (autologous tissue) to create a breast (e.g. deep inferior epigastric perforator (DIEP flap); Allen & Treece, 1994) or a combination of both procedures (e.g. latissimus dorsi flap and implant).

While a number of reviews have found overall good levels of satisfaction with breast reconstructive surgery (e.g. Guyomard, Leinster & Wilkinson, 2007) other studies not included in such reviews provide evidence that reconstructive surgery does not always meet women's expectations (e.g. Crompvoets, 2006). Pain, hardness in the breast and a lack of breast symmetry are commonly reported (Contant, van Wersch, Menke-Pluymers, Wai, Eggermont & van Geel (2004). The systematic review by Guyomard and colleagues (2007) highlights the limitations of studies assessing patient satisfaction with reconstruction. They observed numerous methodological issues including small sample sizes, the predominant use of convenience samples, limited use of validated

questionnaires and exploration of the meaning of satisfaction as well as lack of methodological homogeneity.

A retrospective case note study (Venus & Prinsloo, 2010) from one UK hospital of immediate breast reconstruction using the pedicled latissimusdorsi flap with a silicone implant reported that the majority of patients were satisfied with their reconstruction. High scores were reported in relation to women's perceptions of their appearance when wearing a bra. Progressively lower satisfaction scores were reported for perceptions of appearance when not wearing a bra and for symmetry though these scores remained above the mid-point of the satisfaction scale. The study notes few complications though acknowledged that capsular contracture rates may be higher in a longer-term follow-up as this is often a delayed effect that can occur several years post-surgery.

Interestingly, satisfaction with breast reconstruction has been found to vary between countries. In a comparison of 182 pairs of British and French patients and their partners (split equally between the two countries), British patients reported significantly higher satisfaction due to a closer match between their expectation and the outcome (Guyomard, Leinster, Wilkinson, Servant & Pereira, 2009). No differences were identified between patients and their partners' satisfaction. In terms of factors affecting satisfaction, statistically significant differences were found in the decision-making process with Consultants and partners being viewed as more influential in France, which the authors attribute in part to a greater emphasis on body image in French culture particularly given French women's greater desire to 'preserve their femininity' (p. 786). Higher satisfaction with pain management was reported in France though British women were more confident following reconstruction. The

authors note that breast reconstruction is twice as common in France and highlight differences in the two healthcare systems with a French medical team performing both mastectomy and reconstruction while in the UK two separate teams perform the surgeries. Furthermore, implants are the primary method of reconstruction in France whereas in the UK a mixture of implants, latissimus dorsi (LD) and deep inferior epigastric perforator (DIEP) flap procedures are undertaken. The study is however limited by the use of retrospective self-report measures.

Most recently pioneering skin-sparing and nipple-sparing procedures (the latter in select cases) have been undertaken in one stage as opposed to two thereby reducing the number of required surgeries. The study reported excellent aesthetic results for immediate reconstruction with silicone implants with low rates of complications in 220 women undergoing treatment in Italy (Salgarello, Barone-Adesi, Terribile & Masetti, 2011). In one of the few qualitative studies exploring motives for women's decisions regarding type of reconstructive surgery thirty one women from the Netherlands were interviewed in accordance with a phenomenological approach (Gopie et al., 2011). Women opting for implant breast reconstruction were found to describe surgery-related issues such as a shorter recovery time, less impact of surgery, being able to regain their daily lives and less scarring as key factors influencing their decision. Women opting for DIEP flap were predominantly concerned with regaining a natural breast that would be more symmetrical and believed that this offered a safer long-term solution as implants would require revision at a later date. The opportunity to have an abdominoplasty as part of the operation and the hope that this procedure would improve the sexual relationship with their partner were also motives discussed by women opting for a DIEP flap. This study additionally

revealed that women undergoing delayed breast reconstruction perceived a need to recover from their breast cancer treatment whereas women having immediate breast reconstruction were not concerned with its timing. For the women undergoing mastectomy, reconstructive surgery was viewed as an integral part of the procedure to regain a complete body image. However, the study is limited in that not all women included in this study had received a diagnosis of breast cancer and interviews were undertaken prior to surgery. The influence of healthcare professionals in the decision-making process pertaining to immediate or delayed reconstruction was also not discussed and long-term review of women's motivations and greater in-depth study of the role of breast cancer in this context may elicit different findings.

#### ***1.6.4 Lymph node assessment***

The disease status of the axillary lymph nodes (lymph nodes under the arm) is the most significant prognostic indicator for women with early breast cancer (Veronesi, Galimberti, Zurrada, Merson, Greco & Luini, 1993). Assessment of the lymph nodes is essential for determining staging and prognosis, as well as to guide treatment decision-making (Lyman et al., 2005). Furthermore, in women with spread to these lymph nodes, axillary clearance aims to treat metastases through surgical removal (Veronesi et al., 1993). While technology such as ultrasonography can often identify potentially diseased nodes, failure to detect small metastases and false negative results are common (Lyman et al., 2005). Consequently, histological examination of removed tissue is believed to be the most accurate method of lymph node assessment (Lyman et al., 2005). However, surgery to the axilla, particularly axillary clearance, is associated with morbidity including lymphedema (excessive fluid build-up in the arm as a result

of a blockage of the lymph nodes), shoulder dysfunction and nerve injury (Chetty, Jack, Prescott, Tyler & Rodger, 2000).

Attempts to minimise such morbidity especially in women undergoing staging who are found to be node negative has led to the development of dual localisation sentinel lymph node biopsy (SLNB). Unlike standard axillary node sampling in which a minimum of four individual lymph nodes are chosen from the axillary fat, the SLNB procedure (which can be undertaken via standard or endoscopic methods) involves the selective removal of the first draining nodes (SIGN, 2005). Systematic studies have shown that breast cancer spreads to the sentinel lymph nodes (SLN) prior to other axillary nodes and that SLNB, if performed in selected patients with early stage breast cancer, can reduce the need for axillary dissection and avoid the associated morbidity (Veronesi et al., 2003). In the UK the National Institute for Health and Clinical Excellence (2009) has stated a preference for the use of SLNB for staging the axilla in radiologically or cytologically (where tested) node-negative patients. Women with ductal carcinoma in situ who are having a mastectomy or who may be at risk of invasive disease should also be offered this procedure (NICE, 2009). If cancer is found in the sentinel lymph nodes women should be offered removal of some of the remaining lymph nodes, axillary lymph node dissection (NICE, 2009).

Analysis techniques have been developed such that intraoperative analysis of sentinel lymph nodes can be undertaken enabling node positive patients to undergo immediate axillary clearance (Byrne, Cutress, Gill, Wise, Yiangou & Agrawal, 2012). However, as this facility is not available in all relevant settings in the UK, many patients are required to wait for histology results (Byrne et al.,

2012) and those who are found to have metastases in the sentinel lymph nodes (approximately 30%) undergo a delayed completion axillary dissection (Mansel et al., 2006). Following surgery women may be offered further treatment in an attempt to eradicate any remaining cancer cells and this is considered in the subsequent sub-section.

### ***1.6.5 Adjuvant therapy***

In the UK, in addition to information regarding tumour grade, size and nodal status, post-surgical histological examination also evaluates hormone receptor and human epidermal growth factor receptor 2 (HER2) status (NICE, 2009). It has been estimated that approximately 75% of breast cancers are oestrogen receptor (ER) positive (i.e. oestrogen stimulates the growth of breast cancer) (Anderson, Chatterjee, Ershler & Brawley, 2002). Consequently, stopping or lowering the level of this hormone via targeted endocrine therapy, such as Tamoxifen, can help to treat ER positive cancers. The daily self-administration of Tamoxifen for up to five years post-surgery is the standard treatment for women with these tumours who are pre-menopausal at diagnosis (NICE, 2009). Trials have shown that Tamoxifen, which works as an aromatase inhibitor reducing the level of oestrogen, reduces the risk of local recurrence and breast cancer mortality irrespective of age and menopausal status (Early Breast Cancer Trialists' Collaborative Group, 2005).

Approximately 15-25% of breast cancers are HER2 positive indicating that this protein is encouraging the growth of breast cancer (Smith et al., 2007). HER2 positive breast cancers are associated with aggressive disease, higher likelihood of recurrence and poor prognosis (Baselga, Perez, Pienkowski & Bell, 2006). Treatment with targeted therapies (e.g. Trastuzumab, otherwise known



by the brand name Herceptin) may be used to block the effects of HER2. This drug, administered intravenously over the course of an hour, is typically undertaken once a week every three weeks for early breast cancer and weekly for more advanced breast cancers (Department of Health, 2009a). However, this treatment is not suitable for women with heart problems or uncontrolled high blood pressure.

NICE (2009) recommends that given the prognostic value of ER and HER2 status, such histological results should be made available to the multidisciplinary team to guide decisions regarding adjuvant treatment. Computer programmes such as Adjuvant! Online (Ravdin et al., 2001) which are designed to help inform discussions between patients and healthcare professionals as to the benefits of adjuvant therapy may support the decision-making process. This tool takes into account patient age, tumour size, histological grade, hormonal receptor status and comorbidities to predict disease course and potentially effective treatment(s). However, the current version does not include HER2 status and variation in the use and interpretation of such web-based tools may lead to some women with early stage breast cancer being under- or over-treated with chemotherapy (NICE, 2012).

Chemotherapy, the use of anti-cancer (cytotoxic) drugs to kill cancer cells, or shrink larger tumours, is usually given after surgery if the tumour is large, of a high grade, HER2 positive or if a triple negative result is obtained (negative for oestrogen, progesterone and HER2) and if cancer cells are detected in the lymph nodes (Macmillan Cancer Support, 2011). If breast cancer is in an advanced form and has spread to other organs in the body chemotherapy may be utilised to shrink the tumour, relieve symptoms and help to lengthen life

(Department of Health, 2010). Several different drugs are commonly used often in combination though the exact prescription depends upon the type of breast cancer and the extent of spread (NICE, 2009). Chemotherapy is usually given as an outpatient treatment either intravenously or in tablet form and treatments are typically scheduled once every two to three weeks over a period of four to eight months (Department of Health, 2010).

Chemotherapy has the ability to stop the production of oestrogen and as a consequence some women may enter an early menopause as a result of this treatment. Additional side-effects include nausea/vomiting, decreased appetite, fatigue, hair loss, a sore mouth and infections caused by the influence of chemotherapy on healthy cells such as immune cells (Department of Health, 2010). In response to the notion of the over-use of chemotherapy particularly given the toxic side-effects associated with this treatment, a new test called IHC4 has been developed in the UK. This molecular test aims to identify women with oestrogen receptor positive breast cancer who would benefit from chemotherapy as well as those who are at a low-risk of recurrence (Barton et al., 2012). In a recent appraisal by the National Institute for Health and Clinical Excellence (2012) the IHC4 test was thought to have promise given the relatively low financial cost of approximately £100-200 per test (a fraction of the cost of alternative tests).

Chemotherapy is commonly used in combination with other treatments such as Tamoxifen or Herceptin and/or radiotherapy. Irrespective of whether chemotherapy or radiotherapy is undertaken first, guidance states that treatment should commence 31 days from agreement of the treatment plan (NICE, 2009). Radiotherapy uses controlled doses of radiation to kill or damage

cancer cells (Cancer Research UK, 2009). While it was widely believed that radiotherapy would not have a key role in the treatment of cancer (National Radiotherapy Advisory Group, 2007), radiotherapy has continued to play an important part in cancer care and demand for this treatment has increased rapidly (Williams, Summers, Drinkwater & Barrett, 2007). Insufficient radiotherapy capacity has resulted with regards to both workforce and equipment which has, in turn, had a negative effect on waiting times (Cancer Research UK, 2009). This issue may have particular pertinence to breast cancer given increasing incidence rates. With regards to breast cancer treatment considerable variation in access to radiotherapy between cancer networks across the UK and increasing waiting times have been reported (Jack, Davies, Robinson, Sainsbury & Møller, 2007). The recent extension to radiotherapy of the national target of 31 days from agreement of treatment plan to commencing treatment (National Cancer Reform Strategy, 2007) has been deemed unachievable for many parts of the UK (Cancer Partners UK, 2010). Furthermore, in the USA and many European countries a waiting time for radiotherapy of more than seven days would be considered unacceptable (Cancer Partners UK, 2010). It is believed that some variation in access to radiotherapy across the UK may be linked to socioeconomic status with fewer patients receiving radiotherapy in regions with higher deprivation such as the North East of England (Williams, 2009).

In line with international standards on the treatment of breast cancer, external radiotherapy is typically administered daily (Monday to Friday) for five weeks though shorter fractionation schedules are common practice in the UK (NICE, 2009). NICE guidance (2009) states that radiation may be applied to the remaining breast tissue following breast conserving surgery (including for

women diagnosed with DCIS) and to the chest wall following mastectomy to complete local treatment. A boost of high dose radiation (breast boost) may also be offered to women undergoing breast conserving surgery in the area where the cancer was removed however this may affect the appearance of the breast particularly for women with larger breasts. Women considered to be at a high risk of regional relapse may also be offered radiotherapy to the lymph nodes (NICE, 2009). However, despite such guidance variation in the use of post-mastectomy radiotherapy persists in the UK for women at an intermediate risk of local recurrence and patients diagnosed with ductal carcinoma in situ (Mallon & McIntosh, 2012). The advancement of radiotherapy technologies which are more effective at targeting the tumour and sparing surrounding 'normal' tissue may further increase the demand for radiotherapy (Cancer Research UK, 2009b). However, side-effects can occur including irritation and darkening of the skin, fatigue and lymphedema (Breast Cancer Care, 2012).

Pre-menopausal women with early invasive oestrogen receptor positive breast cancer who have chosen not to have chemotherapy in addition to taking Tamoxifen may be offered ovary ablation. This may be via low dose radiotherapy or surgery to remove the ovaries, though these methods are permanent and do bring about the menopause (Breakthrough Breast Cancer, 2009). Alternatively, ovary suppression using a drug called Goserelin, a luteinising hormone-releasing hormone agonist, can temporarily stop women's periods though in those closer to menopausal age this may not occur following treatment completion (NICE, 2009). As has been demonstrated throughout this sub-section treatment options vary given a range of factors including prognostic indicators. Furthermore, the use of technology by the multidisciplinary team to aid treatment decision-making is increasingly prevalent yet would seem to

contradict the notion of encouraging women's participation in making treatment decisions, a topic that is discussed further in the following sub-section.

### ***1.6.6 Treatment decision-making***

Concerns about overtreatment in conjunction with the emergence of the feminist and consumerist movements during the 1980s sparked an interest in treatment decision-making (Lerner, 2001). The majority of treatment decisions are made within the first weeks following diagnosis and surgical decisions are typically made during the first consultation with the assigned surgeon (Katz & Hawley, 2007). The level of patient involvement in treatment decision-making has received particular attention though is marked by contradictory findings and potentially influential differences in the study samples used. Rates of passivity in treatment decision-making by women with newly diagnosed breast cancer have, for example, been reported to be as high as 40% (Vogel, Helmes & Hasenburg, 2008) and as low as 8% (Lam, Fielding, Chan, Chow and Ho, 2003). The findings of research, such as that of Vogel, Helmes and Hasenburg (2008), assessing patient involvement in treatment decision-making ought to be considered in light of numerous limitations. Differences between study participants and non-responders are commonly reported thereby restricting generalisability. The use of self-report measures and inherent difficulties measuring multifactorial constructs like decision-making via forced choice questionnaires are further issues. What is more, given the nature of the disease equal treatment options are not always available for all women though this is often not taken into account.

In the aforementioned study by Vogel and colleagues a further 31% of patients wanted to select their own treatment while 29% wanted collaboration. It is this notion of shared decision-making that is at the core of the latest Government White Paper for Health (2010) promoting "involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone" (p. 13). Conceptually, consensus on the meaning of shared treatment decision-making has yet to be reached and the steps clinicians can use to implement this approach lacks definition (Moumjid, Gafni, Bremond & Carrere, 2007). Attempts to measure shared decision-making, particularly in the context of breast cancer where women are encouraged to bring a significant other to medical encounters resulting in a triad as opposed to a dyad interaction, are problematic and lack empirical study as the notion of shared decision-making is open to interpretation (Charles, Gafni & Freeman, 2010).

Women who do actively engage in treatment decision-making have been found to report a significantly higher quality of life than those opting for a passive role (Hack, Degner, Watson & Sinha, 2006) and may lead to better long-term health outcomes (e.g. Anderson, Bowen, Morea, Stein & Baker, 2009). Such studies typically use relatively large samples, 205 women in the research of Hack and colleagues with this study additionally reporting a statistically significant number of women reporting decisional role regret with many preferring more active involvement than had been enabled. A lack of assessment of quality of life at baseline and a retrospective measure of preferred involvement somewhat limit the reliability of the findings. By contrast, qualitative content analysis of women's accounts pertaining to treatment decision-making on a popular UK breast cancer website revealed that women often willingly handed over control

to healthcare professionals due to the difficulties and stress experienced following diagnosis and in making decisions of such importance (Seale, 2005).

The quality of decision-making has been assessed via satisfaction surveys with research frequently using measures of women's desired versus actual levels of decisional involvement. However, incongruous findings are commonplace and the majority of such studies focus on surgical decisions and are conducted in the USA and Canada impacting upon UK applicability. While some research indicates that over half of women with breast cancer do not attain their desired level of involvement (Degner et al., 1997), Temple and colleagues (2006) reported that 60% of their sample of 157 women believed that they had participated in treatment decision-making to their desired level. Nevertheless, achieving the desired level of involvement has been linked to greater satisfaction with breast cancer treatment decisions suggesting that the process may be as crucial as the decision made (Sabo, St-Jaques & Rayson, 2007).

Contrary to the underlying premise of involving patients to reduce unnecessary surgery greater patient involvement in decision-making has been found to be associated with more invasive treatment i.e. mastectomy (Katz et al., 2005). A variety of factors have been attributed to women's decisions to undergo mastectomy including for "peace of mind", to lower the risk of local recurrence and to avoid radiotherapy (Collins et al., 2009). In a prospective cohort study of 157 women's surgical treatment decisions (Temple et al., 2006) women cited doctors' advice and potential for a complete cure as key deciders.

To explore women's perspectives of breast cancer treatment decision-making O'Brien and colleagues (2008) used qualitative interviewing with video-stimulated recall with twenty one women considering surgery and adjuvant

therapy. Treatment decision-making was found to commence soon after diagnosis involving several processes including information gathering and identifying preferred treatment options prior to the surgical/oncology consultation though women continued to rely heavily on information provided by healthcare professionals. Measures to enhance the study's rigour were undertaken however, it is possible that participants' perceptions of treatment decision-making and behaviour during consultations were influenced by the videotaping and interview process. Indeed, rather than aid recall the authors acknowledge that the video often served to provide women with another opportunity to reflect on the consultation as they had forgotten or misinterpreted details since the consultation occurred.

Presenting conceptual models of decision-making women's reaction to their diagnosis, information provision, perceived sense of urgency, prior knowledge of cancer, women's body image and supportive relationships in women's lives were considered influential in early breast cancer treatment decision-making (Halkett, Arbon, Scutter & Borg, 2005). In a qualitative hermeneutic phenomenological interview study with 18 women the authors (Halkett, Arbon, Scutter & Borg, 2007) later documented that the multitude of decisions women are required to make following diagnosis result in emotional challenges and that women perceived a need to prepare for such decision-making. Having support from family and friends in making decisions was viewed as of importance and the decisions made were deemed to affect women's lives in the long-term. Women did not participate in this study until after surgery and all adjuvant therapies had been completed though details of the timing of interviews and which treatments were undertaken by the women participating were not stated. Thomas-MacLean (2004a) also reported the difficulties women face when



making treatment decisions and noted that these decisions are often questioned even after treatment completion.

Research considering non-surgical treatment decisions is particularly limited. One qualitative focus group study exploring chemotherapy decisions in 34 older women with breast cancer found that the majority of women did not believe that they had a choice though they preferred this non-involvement (Kreling, Figueiredo, Sheppard & Mandelblatt, 2006). Conducted in the USA the sample of ethnically diverse women including a high proportion of African-American and Latina women over 65 years of age limits the transferability of the findings to the UK. The time elapsed between diagnosis and focus group participation also varied widely from one to ten years bringing the possibility of recall bias.

Designed to be understood by lay individuals and therefore help patients with cancer who desire involvement in treatment decision-making, decision-aids were introduced to provide disease-specific knowledge and information on treatment regimes (Vodermaier, Caspari, Wang, Koehm, Ditsch & Untch, 2011). Systematic reviews and meta-analyses have shown that decision-aids increase the likelihood of patient participation as well as disease and treatment knowledge and decrease decisional conflict (e.g. O'Brien et al., 2009; Vodermaier et al., 2011; Waljee, Rogers & Alderman, 2007). Research conducted to determine whether decision aids can influence outcomes such as anxiety and depressive symptoms, quality of life or body image have however been inconclusive. Issues relating to the methodologies of primary empirical studies including modest sample sizes, post-randomisation exclusions, multiple treatment interference and limited reliability of the measures used may help to

explain contradictory findings. Involving women in aspects of breast cancer care extends to follow-up practices and is discussed in the next segment.

### **1.6.7 Follow-up**

Following treatment completion women are entitled to undergo a mammogram every year either up until the age at which they are entered into the NHS Breast Screening Programme or if already over 47 years every year until five years post diagnosis. Routine follow-up appointments are also provided by either the GP practice, the breast clinic or a combination of these services in line with women's preferences. Randomised trials conducted in the UK provide evidence that follow-up care by a woman's general practitioner is equivalent to hospital-based outpatient care in detecting cancer recurrence (Grunfeld et al., 1996). Furthermore, this level of care elicits a high level of patient satisfaction and greater cost-effectiveness than specialist hospital care (Grunfeld et al., 1999a; Grunfeld et al., 1999b). This may become of increasing importance given the growing demand for follow-up services by breast cancer survivors.

## **1.7 Survivorship**

Increases in breast cancer survival due to improvements in early detection and treatment have resulted in women diagnosed with early node-negative breast cancer having a 95-98% survival in many countries (Cancer Research UK, 2011). Consequently, in conjunction with general gains in life expectancy, there are a large number of women living with the long-term effects of breast cancer and its treatment (Brennan & Houssami, 2011). In acknowledgment of such factors cancer has been re-categorised from an acute illness to a chronic illness

(Tritter and Calnan, 2002). The issue of survivorship was raised in the Cancer Reform Strategy (Department of Health, 2007) which announced the National Survivorship Initiative recognising the long-term impact of a cancer diagnosis and treatment. A review of the long-term care needs of breast cancer survivors (Brennan & Houssami, 2011) illustrated that the management of treatment side-effects such as premature menopause and lymphoedema in addition to care relating to bone health, psycho-social and sexual health as well as evaluation of risk factors require attention if women's long-term needs are to be met. The psychological aspects of women's experiences are discussed further in the following literature review chapters and the need for longitudinal research in particular is highlighted.

## **1.8 Chapter summary**

While providing contextual information, the content of this chapter also reflects the domination of the breast cancer literature by medical aspects of the disease from prevalence and risk to the efficacy of screening and treatment modalities. Indeed, women's experiences can incorporate a multitude of diagnostic tests and treatments and women are increasingly encouraged to actively participate in making treatment decisions that may influence their physical and psychological well-being as well as their future. However, treatment decision-making is a complex process and our understanding of women's perceptions and experiences in relation to the wide range of available treatments is limited particularly given the shortcomings of existing studies and specifically the lack of applicability to the UK. Furthermore, the focus of the medical model on cure/treatment leads to a neglect of the chronic nature of breast cancer and the long-term physical and psychological effects that are emerging as being

associated with survivorship. The following chapter begins to review the psychological impact of breast cancer through exploration of the illness experience framed by theories of self, identity, and embodiment. The influence of the biomedical model is additionally considered in relation to women's relationships with their bodies and experiences.

## **CHAPTER 2: THE ILLNESS EXPERIENCE OF BREAST CANCER: SELF, IDENTITY, BODY AND EMBODIMENT**

### **2.1 Introduction**

Research on the illness experience is wide-ranging encompassing a number of areas from the meanings ascribed to illness, to the impact of illness on individuals' lives, sense of self and the coping strategies (discussed in chapter 3) they employ throughout their experience. As described in Chapter 1 (p. 42), breast cancer constitutes a chronic illness and for many women can involve lengthy treatment regimes which have the potential to change women's bodies (via both surgical and non-surgical interventions) and sense of self. Furthermore, long-term immersion in the medical model has further potential to have an enduring impact on the relationship between women's body and self. Accordingly, this chapter reviews the prevailing theories of self, identity and embodiment. The specific gender connotations a breast cancer diagnosis can elicit are highlighted and the existing application of the aforementioned theories to the illness experience and breast cancer are discussed.

### **2.2 Self and identity theory**

The study of self and identity is marked by confusion in the multitude of language used to analyse selfhood. Terms such as 'the subject', 'identity', 'the self', 'self-identity' and 'self-concept' are often used interchangeably. Differences in terminology reflect historical and political transitions and the use of these terms by a large number of disciplines, each with its own theoretical and methodological standpoints (Stevens, 1996) adds ambiguity and complexity to the literature base. Furthermore, colloquial understandings of self and identity permeate everyday life and as noted by Baumeister (1986) both terms are

social constructions and that defining something that does not exist is fraught with difficulty. While many writers choose not to differentiate between 'self' and 'identity' (e.g. Piot-Ziegler, Sassi, Rafoul, & Delaloye, 2010) others argue against this stating that there are forms of identity that are not based on the self (e.g. collective identities). Despite debate regarding definitions, the study of self and identity remains central to the exploration of human behaviour and experience and the relationship between social life and subjectivity (Wetherell, 2009).

Philosophical and theological traditions discussed self and identity as early as the 1690s and established psychological and sociological literature on this topic dates back to the late nineteenth century with James' classic text in 1890 (James, 1950). The 1950s saw an increased interest in the topic as it moved into mainstream psychology though was heavily influenced by sociological conceptions of self and identity (e.g. Goffman, 1959). Developments were made in the realms of personality (Snyder, 1974) and cognitive psychology (Markus, 1977), all of which set the scene for exploration of a multifaceted self featuring enduring and changing components (Swann, 1983).

### ***2.2.1 Defining the self***

Numerous writers have attempted to capture the meaning of 'self' such as Charmaz (1987) who refers to the concept of self as "an emergent structure or organisation as it may shift or change as the person reflexively interprets the identification it imagines that self or others confer upon him or her" (p. 284). In other words, self is how one views oneself, otherwise termed self-concept, and is the product of relationships and interactions with others (Charmaz, 1983). Alternate definitions view self as "the autobiographical narrative used to account

for and explain the life world of the narrating "I" (Kelly & Dickinson, 1997; p. 254). Self can also be defined in terms of one's personality, the combination of an individual's temperament, abilities, goals and values, and is what makes them unique, differentiating them from others (Tesser, 2002). It is additionally viewed by some as an executive agent regulating one's behaviour (Epstein, 1975 as cited in Bertero & Wilmoth, 2007) and as a psychological entity that is the subject of a person's experiences, an inner being, it is "me".

A distinction between an inner and outer self has been proposed on the basis of the philosophy of Levinas (1991) whereby the inner self may be described as the soul and is the private element of the self. Conversely, the outer self acts within the social world in terms of our habits and discourse as well as framing thought processes resultant to socialisation (van Wersch, 2001). As such, perceptions of self can be said to be context-dependent as how the self is experienced in a specific instance depends on time and place and specific historical, social and material circumstances (Goffman, 1959). It seems that most commonly, the term self refers to a representation or set of representations about oneself. It is the beliefs, perceptions, values and thoughts that people have about themselves.

Harre (1998) expanded discussion of the components of self to describe three senses of self. The first, termed self-1, relates to the notion that each person has a unique viewpoint of the world from which to perceive and act upon the environment. In other words, self-1 has a sense of self as perceiver and actor, having a place in the world of things and events. Self-2 describes the concept that each person exercises their powers to display a unique set of attributes and with this goes the sense of totality of those attributes, at least what the person

believes them to be. Our culture and social positions are manifested in our bodily dispositions and tastes. Self-3 refers to the sort of person that we are taken by others to be. This stems from how our attributes are expressed publicly and in turn give rise to the beliefs and opinions of others. Self-3 is however complicated by the self that individuals want to project.

### ***2.2.2 Concepts of identity***

Harre's (1998) three aspects of personhood or self reflect the idea of personal (or individual) identity but he emphasises that in contemporary writing an individual's identity is not his or her singularity as a unique person but rather the group, class or type to which they belong. This description of social identity dates back to Gergen's work during the early 1970s and broadly refers to membership in social categories (Gergen, 1991). It requires distinguishing those who share an identity from those who do not, the marking out of "us" and "them" (Woodward, 2002). In laying claim to such an identity we assign a label to ourselves and to others.

The concepts of individual and social identity are, however, not mutually exclusive. Who we are perceived to be by others (and the groups with which we are perceived to belong) may in turn influence how we see ourselves (e.g. Brewer, 2001) and result in a reaction to who the social world is defining us as being. Empirically speaking, identity comprises both personal and social components in varying combinations depending on social context (Oakes, Haslam & Turner, 1994). In addition, increasing globalisation and a continually changing human experience has led postmodern authors to acknowledge that individuals manage multiple and often conflicting identities (Frie, 2011). In the



case of women this may include identities such as that of wife, mother, and worker. However, a diagnosis of breast cancer may also elicit a renegotiation of a healthy identity to that of a 'patient' (Mathieson & Stam, 1995) as individuals attempt to become familiar with relevant medical discourse in order to express concerns and help them to navigate the healthcare system. Longitudinal exploration of the illness experience, as in the present study, may be particularly valuable in identifying multiple identities, including that of 'cancer patient' as well as revealing any changes to these identities throughout the healthcare trajectory.

A further notion of identity that many researchers (e.g. Harre) do not explicitly discuss is that our identities are, in a sense, also those of our bodies. It can be argued that the body is a resource for interaction in the world as through the body an individual communicates and performs actions and tasks and consequently has meaning in the social world for its inhabitant and others (Corbin and Strauss, 1988). The body has become central to determining who we are and is the medium via which our identities can be conveyed and therefore can be observed as a representation of the self (Shilling, 1993). The body can provide a sense of certainty about who we are, about our identity, however the bodies we inhabit offer limitations to the identities to which we might like to lay claim (Woodward, 2002).

### ***2.2.3 Self and identity in illness***

As noted by Mercer (1990) "identity only becomes an issue when it is in crisis" (p.43) such as at times of illness and disability. Writers including Bury (1982, 2001) and Frank (1997) have conceptualised the impact of illness on the self as

a biographical disruption whereby the story constructed by an individual about their past, present and future, their life, is interpreted and changed as a result of illness. Frank (1997) speaks of this in terms of a loss of destination or map of the future as plans are postponed or cancelled due to the physical limitations acquired through illness. Contemporary theories of self attempt to estimate the degree to which self may be fragmenting or breaking down (Elliott, 2008). Disruption to everyday tasks and daily habits elicited by illness and treatment regimes alter an individual's way of being in the world and challenges their ideas about their notion of self leading to new levels of insight (Goud, 1995). Clarke and James (2003) argue that in acquiring and accepting a medical diagnosis, an individual adopts a "transitional identity" as a person whose body is temporarily in poor functioning order, a person in a "special medically legitimated place in the social order" (p. 1993). This label enables the individual to accept a medicalised yet normal self (Tishelman and Sachs, 1998).

The self can nevertheless detract and individuals may avoid viewing the self as ill and attempt to maintain an unchanged self, not reconstructing the self until acting in their changed daily lives means they have no choice but to accept an altered self (Charmaz, 2002). Alternatively, they may seek to return to normal, in other words, their life and self as it was prior to illness (restored self) or attempt to develop a self that they perceive to be better than before (supranormal self) (Charmaz, 1987). These theories assume a relatively fixed self to which the actor is trying to adjust and it is the loss of self that Charmaz (1983) argues constitutes a fundamental form of suffering.

#### ***2.2.4 Development of a new self-concept***

The postmodern view of the self, however, is one that is flexible, open to change and is continually being re-written (Bunton, 1997). Authors such as Corbin and Strauss (1988) argue that bodily limitations must now be incorporated into a new self-concept which arises from the development of new habits and ways of acting in the world. Similarly, Frank (1991) states that illness provides an opportunity to develop new behaviours, reassess priorities and reform relationships. In 1993 he described illness as a vehicle for self-transformation suggesting three self-change narratives, the rediscovery of self who has always been; a radical new self that is still evolving; and finally, that there is no "new" self.

Morse (1997) proposes a model of how when experiencing illness an individual might move towards the development of a new self-concept. Stages one and two, 'vigilance and disruption: enduring to survive', occurs during the acute phase of physical illness and relates to how this overshadows an individual's sense of identity, disruption or change. Stage three, 'enduring to live: striving to regain self', refers to how individuals are forced to recognise physical changes and the loss of function that they have experienced. At this stage the individual will start to seek to restore as much physical functioning as possible. The fourth stage, 'suffering: striving to restore self', is concerned with the effects of what has happened now being recognised and how the person begins to struggle with grief and mourning for what has been lost. They begin to hope and set realistic goals for the self while learning to live with difficulties and setbacks but they may also refuse to accept the limitations imposed on them by their illness and still strive for complete physical recovery. Stage five, 'learning to live with the altered self', is about accepting the (potentially changed) body and the

limitations it brings. This latter stage is akin to that of Norris and colleagues (Norris, Kunes-Connell & Stockard-Spelic, 1998) who describe 'reimagining the self' (p. 1). Essentially, learning to live with illness, particularly chronic illness involves changes in identity as the individual grapples with changes in their sense of self that existed prior to the illness (Karnilowicz, 2011). Accordingly, illness can dominate identity and permeate all aspects of life or effect only part of the self (Kralik, Koch, Price & Howard, 2004) and as such these theories may be highly pertinent to the chronic nature of experiencing breast cancer. The following section extends the discussion of the self by considering the relationship between the self and the body.

### **2.3 Embodiment**

Embodiment is viewed as a way of thinking about human beings, one that is in contrast to Western thinking of mind and body as separate (Wilde, 1999). It is often described as being situated in the world, and being affected by social, cultural, political, and historic forces (Benner, 1994) though the term is often used loosely to refer to holistic understandings about life (Wilde, 1999). In replacing Cartesian dualistic notions which objectify the body, having a sense of embodiment is to see the person as a whole, an embodied being. This move enables new ways of thinking about human beings and facilitates the study of taken-for-granted processes in everyday life. The focus on how individuals live and experience the world through their bodies reflects the phenomenological philosophy of Merleau-Ponty (1962) and provides a perspective through which meanings of health and illness can be explored as well as how individuals manage issues in illness.

### ***2.3.1 The impact of illness on embodiment***

In the normal course of events our relationship to our bodies remains largely unproblematic and only during illness does it become the object of attention (Leder, 1990). When the body becomes ill it becomes the central aspect of experience with illness taking over consciousness and dominating the individual's life (Kelly & Field, 1996). Chronic illness focuses an individual's attention on physical activities and bodily functions that were previously taken-for-granted (Leventhal, Idler, & Leventhal, 1999). Illness disrupts the relationship between the self and the body as when the body changes the self becomes uncertain (Conrad, 1987). The body becomes detached from the self reflecting the traditionalist view of the body characterising it almost as a physical machine, animated by a controlling mind, which directs its activities and responses (Radley, 1994). This notion was reinforced by van den Berg (1966) who described how a healthy individual is allowed to be their body yet in illness this assimilation is disturbed and the body becomes foreign and an adversary which the person has to revolt against.

Women frequently talk about their bodies in ways that suggest such fragmentation with the self located 'outside' the body (Williams & Bendelow, 1998). Women in labour talk about 'the contractions' and during menopause discuss 'the hot flushes', not their own, not mine. Accordingly, the body is viewed as separate from the self and is seen as alien and dysfunctional (Williams, 1996). The medical model presupposes a 'self' or 'person' which is embodied in the sense of having a body not in the sense of being a body. As we think of our bodies as something we have, that belongs to us and which we maintain or allow to deteriorate, the medical world becomes primarily concerned with the body and in improving or restoring the place in which we inhabit. In this

context of medicine and illness the body is seen as a physiological system which is understood in terms of concepts that analyse its constituent parts and their relations (Radley, 1996).

### ***2.3.2 Medical objectification of the body***

Once an individual becomes ill their body becomes the object of the doctor's attention and is typically spoken about in terms of the 'diseased body parts'. In relation to cancer people often speak of an invasion inside the body even if the causative agent is external. The disease, for example a tumour, is seen as separate from the self and it is 'the tumour' that requires treatment, as opposed to the person. Cassell (1976) reported how a woman with a mass in her breast spoke of "my breast" and "my nipple" but of the tumour as "it", asking the doctor to "make it go away". Cassell argued that it is the disease itself that is objectified though conceded that this can be dependent upon the disease in question as such objectification has not been found, for example, in relation to diabetes and hypertension. This finding may be linked to the lack of a single body part as a focal point for lay discussions of diabetes and hypertension and perceptions of lower severity of these illnesses as compared with breast cancer.

The medical world can reinforce the separation of body and self objectifying the body by making it a 'physical thing' which is subjected to medical procedures, treatment and prescribed regimens. The body becomes subject to radiation, drugs and/or surgery to make it function properly once more (Radley, 1996). Objectifying a disease such as cancer may however serve the needs of both patients and healthcare professionals helping to "distance that disease and the distress it causes from the person experiencing it" (MacLachlan, 2004, p.27).

This is perhaps self-protective and supportive for the patient and for the doctor who will feel as if they are "fighting an it and not you" (Maclachlan, 2004, p.27). This can be likened to Goffman's (1968) dramaturgical model which refers to how institutionalisation entails a 'stripping of identity' or 'loss of self' to aid patient management. Maclachlan extends this discussion by referring to the objectification of the body resultant to patients trust in doctors and handing over control of the body stating that it is "probably a desire not to be responsible for dismembering oneself" (p.29). This could have particular connotations in relation to breast cancer treatment decision-making.

Furthermore, as people come to regard their body in such a manner they too begin to describe their bodies through highly technical medical language. This communication with health professionals can leave the patient feeling that the medical details of their disease is the only valid focus of their experience but that it is necessary to learn this in order to articulate their concerns (Mathieson & Stam, 1995). They note that this cannot help but present an identity threat to individuals who are already asking themselves 'What does it mean to be a cancer patient?' As this sense of embodiment is renegotiated an individual will in conjunction be bringing together their past and present selves to form a coherent self-identity.

### ***2.3.3 Liminality***

The transition from health to illness and the ensuing disruption to life may be considered through the concept of liminality which is argued to link illness and embodiment (Little, Jordens, Paul, Montgomery & Philipson, 1998). When applied to the narratives of individuals experiencing colon cancer Little et al.

(1998) propose liminality to be a process consisting of two stages. Firstly, upon diagnosis, an individual is theorised to enter into a state of acute liminality, experiencing cancer as an existential threat. The length of time an individual is within this phase is believed to be dependent upon their biography, the nature of the diagnosis, treatment required and prognosis, as well as social support and individual differences. Sustained liminality is purported to follow and is entered as an individual reaches a convalescent phase and begins to reassert control of their lives while managing the uncertainty of cancer which they propose renders liminality an enduring state. The notion of sustained liminality can be likened to Frank's (1995) concept of 'cancer patientness' (p.136), an identity which remains given changes to the self and reinforcement (via the body, self and healthcare system) of being a person who has had cancer. Little et al. (1998) argue that sustained liminality is observed via narratives of experiencing illness through the body and that perceiving bodily limitations is to experience separation of body and self. Accordingly, the concept of liminality may have application to the present study given the potential long-term disruption to women's lives resultant to experiencing a chronic illness and, as discussed further in the remainder of this chapter, the potential impact of breast cancer on the relationship between the body and self.

#### ***2.3.4 Frank's problems of embodiment***

Frank (1995), a key writer on the illness experience and self change, proposes four general problems of embodiment (control, body-relatedness, other-relatedness, and desire) that everyone attempts to resolve throughout their lives yet which require more "self-conscious solutions" (1995, p. 29) during illness. The actions of the self to these four problems are theorised to give way to four



continua of responses. He further describes four ideal typical bodies which are said to characterise a tendency that the self can choose to enact given the problems of embodiment.

The first of these problems refers to the body's capacity to control its functioning. While predictable, control requires no attention however Frank argues that disease is a loss of predictability which can result in losses in bodily functions and that "illness is about learning to live with lost control" (1995, p.30). Where being in control is at one end of the continuum, contingency, a belief that body control is not possible, is at the other. Seeking ultimate predictability or accepting a degree of contingency is the individual's choice when faced with this problem. Body-relatedness is Frank's terminology pertaining to the question 'Do I have a body or am I a body?' Those individuals who are not in contact with their body, or not attending to it, are said to be dissociated from their body. In contrast, others may be living in a body with which they are associated which Frank argues is easy when an individual is healthy and not facing mortality. However during times of illness modern medicine encourages dissociation by focusing on, for example, statistics and diagnostic images rather than patient's bodily awareness. Once again, Frank argues that bodies are neither associated nor dissociated but individuals fall on a continuum between these extremes and that the quality of association changes. In discussing other-relatedness the extremes of dyadic and monadic are utilised when considering the body's relations to others. The dyadic body recognises that while the body is "mine" it is shared and influenced by others while the monadic body is separate and alone. While during illness some individuals choose this latter stance and medicine encourages monadic bodies by limiting patients contact with one another, Frank proposes that illness provides an opportunity for the sharing of

experiences. The final embodiment problem, desire (or wanting more), relates to individuals desires (e.g. for a normal, healthy appearance) and how these are expressed for, with and through the body (e.g. by disguising the impact of treatment).

Frank further presents four theoretical ideal typical bodies that relate to each of the four continua of embodiment problems. These aim to provide a "heuristic guide" (Frank, 1991, p.53) that can be utilised to order and understand behaviour. He describes the body as a moral problem and that "selves act in ways that choose their bodies, but bodies also create selves who act" (Frank, 1995, p. 40). Individuals, particularly during illness, may not choose their bodies yet they remain responsible for their bodies and decide how to exercise this responsibility. The first of Frank's ideal body types is known as the disciplined body and is one characterised by actions of self-regimentation. Given the loss of control experienced during illness this body-self attempts to reassert predictability and in doing so the self becomes dissociated from a body subjected to therapeutic regimes, one that has become "it" to be treated. This body is monadic rarely seeking association with others and lacks desire though make "good patients" in their medical compliance. The narrative of this body-self is not told about itself, but about the pursuit of the regime. For the mirroring body the body is an instrument with the object of consumption, the aim being to recreate the body in the images of other 'ideal' e.g. healthier, bodies - those often depicted in popular culture. The mirroring body again seeks predictability though via appearance and accordingly fears disfigurement. This body-self is associated with its body on a surface level with the visual image being of paramount importance. Acting alone the body is monadic and while producing desires, these too represent its monadic nature as it wants for itself.

The dominating body is one defined in terms of force. It represents ill persons dissociating from their bodies but is dyadic in being linked to others by attempting to control them, displacing their rage against contingency at others. This domination of others Frank argues may reflect the bitterness experienced as a result of the loss of desire of the body-self. The communicative body-self is an idealised type accepting contingency as part of life as well as the fragility of the body. It is associated with itself acknowledging that the body-self is a unity, it is dyadic seeing its own suffering in the others bodies and produces desire, wanting and needing to relieve the suffering of others. This body is a communicating tool in both a verbal and non-verbal sense. Frank related this body to female reproduction and sees communicative potential in the caring practices of medicine.

The naturalistic assumptions in Frank's typology have, however, been highlighted by Halford, Savage and Witz (1997) who note that his notion that the communicative body is uncontrollable is based on visualising menstruation, pregnancy and childbirth in passive terms. Shilling (1993) further states that Frank does not explore whether and how different types of body usage are chosen, changed or socially influenced. Yet, given the potential impact on women's bodies and self, Frank's problems of embodiment and body types may have application to women's experiences of breast cancer by providing a theoretical base to aid understanding of women's responses to the disease.

The previous discussions have shown that questions or concerns about identity and self are closely related to embodiment. "If one accepts that the human body mediates experiences of the self, and that impaired bodies therefore mediate different experiences of the self and the world, then there is value in recognising

someone's physical status, although not defining them by it alone" (MacLachlan 2004; p.72). This quotation illustrates the importance of considering the self and the body during illness and the potential of narratives in exploring meaning and links between individuals, culture and the illness experience. Furthermore, with regards to breast cancer the meanings ascribed to women's breasts and the psychological consequences associated with breast cancer surgery may have an additional impact on women's perceptions of embodiment and sense of self and are discussed in the following section.

## **2.4 Breast cancer and the female body**

### ***2.4.1 The meaning of breasts***

"Women do experience gender in an embodied way: they live in and through their bodies that are marked and framed through discourses and practices of society" (Lee, 1997; p. 455.). Women's perceptions of their bodies and the way with which they speak about their bodies cannot be separated from their experience of them, the way they use their bodies to engage with the world or from the opposing discourses through which we assign meaning to the body (Ciclitira & Weaver, 2002). Women's breasts are imbued with social, cultural and political meanings which shape the way women view and experience their embodied self. Breasts are coded as a marker of womanhood and femininity yet ambiguously both a visual sign of female sexualisation while a symbol of motherhood, being essential for nurturing infants (Wilmoth, Coleman, Smith & Davis, 2004). Women's breasts have become objectified and fetishised with such construction depicting breasts as decorative rather than functional (Millsted & Frith, 2003). Breasts are argued to have become over-sexualised as evidenced by images of topless women in daily national UK newspapers

through which some bodies are judged to be more valuable than others (Brook, 1999). The presentation of these photos of 'perfect' breasts is claimed to make an average woman feel imperfect and can result in the need for psychosexual counselling following breast surgery (Ussher, 1993) given resultant changes to women's body image and sense of self.

Langellier and Sullivan (1998) explored women's discourse and identified four types of talk regarding breasts, the first of which they termed 'medicalised breast' alluding to the construction of breasts as a physical body part with disease. The 'functional breast' was seen as a symbol of women's abilities to emotionally nurture others and the 'gendered breast' viewed breasts as a sign of femininity, beauty and sexual desirability. Finally, the 'sexualised breast' referred to the look and feel of the breast. Langellier and Sullivan proposed that women talk about these types of breasts as belonging to them and their children, husbands and lovers. Meyerowitz and Hart (1996) remark that women with breast cancer are targeted for research due to an underlying assumption that breasts are so central to the sense of womanhood that the illness will destroy women's psychological integrity. Conversely, other researchers argue that it is no more devastating to women than other cancers (Mendelsohn, 1990).

#### ***2.4.2 The impact of breast surgery***

Women's fear of breast loss was illustrated in a Turkish phenomenological study exploring twenty women's experiences of undergoing an excisional breast biopsy (Demir, Donmez, Ozsaker & Diramali, 2008). Although the findings are limited by few available details regarding the study sample and sociocultural specificity it was identified that as well as an intense fear that the lump was

cancerous, women feared that their breast would be removed and several women experienced dreams of this nature. The study additionally reported that women discussed fear of cancer more frequently than fear of breast loss which supports previous findings of Fallowfield and Hall (1991) which indicated that women's primary fear is the fear of cancer.

Furthermore, a qualitative study exploring Taiwanese women's experience about facing mastectomy (Fang, Shu & Fetzer, 2011) revealed that while survival was the priority, as this was necessary to fulfil women's responsibilities (e.g. childrearing), the meaning of the breast was integral to women's deliberations over mastectomy. The authors state that women persuaded themselves to accept mastectomy and an awareness of post-mastectomy alternatives such as reconstructive surgery and external breast prostheses alleviated some of the negative impact associated with breast loss. Moreover, some women in the study discussed how having smaller breasts reduced the effect of mastectomy. This research study employed three individual interviews followed by one focus group of seven women and employed content analysis. The small sample size and specific geographical area as well as recruitment via a support group constitute limitations. In relation to the latter point women who choose not to participate in support groups may have different experiences from women who do so. Finally, the length of time between mastectomy decision-making and data collection was an average of four years which may have influenced recall.

It is widely acknowledged that the loss of one or both breasts may evoke feelings of mutilation and altered body image (e.g. Kunkel, Chen, & Okunlola, 2002) and experiences of emotional pain may continue long after treatment

completion as women grieve for the loss of a breast or feel as if part of them has 'died' (Langellier & Sullivan, 1998). Reporting data resultant from twenty interviews and a further eighteen questionnaires with women from a diverse range of backgrounds Manderson and Stirling (2007) report that women can feel embarrassed, ugly or self-conscious following mastectomy and that breasts are so aligned with the self that having one breast is associated with being 'half a woman' (p.82). This Australian anthropological study focused on women's lexical choices and found that after breast loss women continue to speak of 'the/my breasts' and struggle to find words for the post-mastectomy body. In doing so women frequently refer to the absence of the breast or alternatively speak of the whole self to refer to the absent body part. Importantly, however, only some of the women questioned had undergone mastectomy following a breast cancer diagnosis with others having opted for prophylactic mastectomy.

Women's experiences of altered body image following breast cancer surgery were at the heart of a qualitative phenomenological study of ten Swedish women aged 43-62 years (Lindwall & Bergbom, 2009). Analysis revealed that upon diagnosis women began to perceive their bodies as 'a stranger' (p. 282) and as housing something threatening to their existence and viewed their body as having failed them. Women eluded to the lack of symptoms experienced which they noted made acceptance of losing a breast more difficult. The body became a prison as women became dependent on others given the new limitations imposed by the body. Surgery was identified to be a frightening experience with women reporting being fearful of what the surgeon may find particularly in relation to spread to the lymphatic system yet it was deemed as necessary for survival. After surgery women saw their bodies as forever altered with the scars as reminders of breast cancer and had to learn to live with

different bodily discomforts due to treatment side-effects. The study authors acknowledge several limitations including the small sample size, that all women were married and living with their partners and that participants were interviewed only once between one and five months post-surgery. Furthermore, the majority of the sample underwent mastectomy with three women undergoing bilateral mastectomies and only two women having a lumpectomy. It is possible that women experience post-surgery bodies differently depending upon the type of breast surgery conducted.

Mastectomy patients, for example, have been found to be more likely to dislike their appearance without clothes (e.g. Alicikus et al., 2009) and avoid looking at themselves in the mirror (Langellier & Sullivan, 1998). Van Wersch (2001) additionally comments on the importance of dressing behaviour as identified in several prior studies whereby women undergoing lumpectomy cite relief at not needing to alter their wardrobe and being able to wear their existing clothes. When given the choice of mastectomy or lumpectomy the meaning of a woman's breasts may influence the surgical treatment decision-making process. In a passage from Moch (1995), a book discussing twenty women's breast cancer stories, one woman comments that 'I didn't want to lose my breast...I knew that for sure' (p.14) with Moch adding that for this woman her breasts were too important to her sexually to be completely removed and consequently a lumpectomy was chosen.

In a review of sexuality after breast cancer focusing on published papers (quantitative and qualitative) from 1998 to 2010 Emilee, Ussher and Perz (2010) found that while some women experience positive changes to their sexuality following a diagnosis the vast majority of evidence suggests a range of negative



physical and emotional changes to women's sexuality. Disturbances in sexual functioning, chemically induced menopause, loss of femininity, feelings of sexual unattractiveness, and negative body image were among the factors identified with psychological changes being influenced by social constructions of 'normal' sexuality and femininity. Overall, issues with sexuality and body image in particular were found to be most common during the first year.

Moreover, body image has been reported to be more likely to be affected if a mastectomy had been undertaken rather than breast conserving or reconstructive surgery (e.g. Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006). In a sample of 56 women with breast cancer aged 37 to 68 years Moreira and Canavarro (2010) also found less disturbance to quality of life if breast conserving surgery rather than total mastectomy was undertaken. This study sought to overcome some of the issues prevalent in body image research by adopting a longitudinal approach and use of a multidimensional perspective on body image. In doing so the study examined dimensions of body image (appearance investment, self-consciousness, shame and appearance satisfaction) and psychosocial adjustment (QoL and emotional distress) from the time of surgery (time one) to six months post treatment (time two). The authors reported a significant decrease in anxiety levels over time showing that levels of psychological distress are higher during the initial phase of the illness. Moreover, measures taken at time one demonstrated that women's perceived importance of their body and having a mastectomy compared with breast conserving surgery were predictors of subsequent appearance satisfaction, self-consciousness of appearance and body shame. In relation to body image only body shame increased over time and initial body image was not found to predict later adjustment. This Portuguese study, however, lacked baseline assessment

of all study variables, including body image, prior to surgery. Furthermore, the timing of the first assessment point two to four days post-surgery may have influenced the findings as many women were yet to observe the bodily changes resulting from surgery. An issue pertaining to the internal consistency of one of the quality of life measures was additionally acknowledged by the researchers who also note that a behavioural dimension of body image was not considered in the study.

Similarly, a cross-sectional survey of one hundred women in Brazil concluded that measures related to sexuality were on the whole unfavourable following mastectomy (Manganiello, Hoga, Reberte, Miranda & Rocha, 2011). Sexuality was most affected in women with low educational level, those with older partners, and women who did not have a breast reconstruction. The study limitations do, nevertheless, include the use of a cross-sectional design, relatively low number of participants, and sample characteristics commensurate with a Latina population, which limit applicability to other populations. This section has reviewed the psychological impact of breast surgery including the effects on women's body image and sexuality. In the discussion that follows, the emphasis on disguising breast surgery via reconstruction and the wearing of external breast prostheses is highlighted and the implications of doing so in relation to the self is considered. The content of these two sections may be particularly pertinent to the present study given the high rate of mastectomies conducted in the North East of England (see Chapter 1, p.26).

#### ***2.4.3 Reconstruction and prostheses as the norm***

Young (1992) argues that Western medicine's objectification of the body has led to women's breasts being viewed as detachable and replaceable. Indeed, it is

very uncommon for a woman who has undergone mastectomy to forego reconstructive surgery or the use of a prosthesis (Crouch & McKenzie, 2000). However, Matuschka who bared her mastectomy scar on the cover of New York Times magazine in 1993 writes "If we keep quiet about what mastectomy does to women's bodies, if we refuse to accept women's bodies in whatever condition they are in, we are doing a disservice to womankind" (1993, p.162). Women have reported wearing a prosthesis to appear 'normal' to those in public and to avoid being viewed as asymmetrical or less than whole by male partners, husbands and children (Manderson & Stirling, 2007). This is exemplified by Thomas-MacLean's (2005) study through which interviews revealed women's descriptions of feeling a loss of symmetry and that surgery had led them to 'manage appearances' or 'hide their deformity' from others.

Similar findings were reported following a series of focus groups exploring women's experiences of external breast prostheses (Roberts, Livingston, White & Gibbs, 2003). Twelve women recently fitted with a prosthesis, fourteen breast care nurses and thirteen prosthesis fitters participated in this Australian study. Prostheses were described as restoring women's impaired body image, sense of normality and feminine identity. Nevertheless, women's initial reactions to their use was generally found to be negative given practical problems such as dislodgement, restricted choice of clothing, sweating in warm weather and discomfort due to the weight of the prosthesis. Many women chose not to wear their prosthesis when at home alone and viewed the prosthesis as a foreign object which served as a constant reminder of their breast loss. Adjustment to the use of a breast prosthesis was found to improve over time though provision of sufficient information and support, characteristics of the fitter and the fitting experience aided women's acceptance and satisfaction with their prosthesis. A

lack of information regarding the focus group participants, however, somewhat limits the interpretation of the study findings. The homogenous nature of the small sample particularly with regards to the women who had experienced breast cancer and mastectomy is an additional limitation. All such women were considered to have adequate spoken and written English and were identified as being better informed about prostheses than women for whom English was not their first language. Furthermore, these study participants were treated in a public hospital which had a high presence of breast care nurses.

Through three case studies Bredin (1999) illustrated that mastectomy changes the female body, self and social identity, the latter via concealment, withdrawal, self-consciousness and changed behaviour with others. Bredin argues that conventional medicine reinforces the concealment of problems experienced by some women in living with an altered body image despite the use of prostheses to enable them to conform to "normality". The women depicted in Bredin's study participated as they were experiencing difficulties adjusting to their changed body image and in conjunction with the small sample size these cases may not be typical of women's responses to mastectomy.

Support for Bredin's conclusions comes from Spence (2001), who after personally experiencing breast cancer notes that mastectomy can result in not only the loss of a breast but in the loss of social identity. Spence comments that breast cancer professionals assume that female identity is totally invested in 'femininity' and they too focus on their ability to reconstruct women. However, if a woman does not choose reconstruction or the use of prosthesis she, by default, chooses a desexualised image and loses her feminine social identity.

What is more, this has led to the argument that a prosthesis not only hides the lack of symmetry but is a disguise for those who do not wish to be regarded by others as potentially doomed. In an exploratory study of data collected over two interviews undertaken six to eight weeks apart with seven women who had undergone mastectomy Crouch and McKenzie (2000) concluded that from the moment a woman is diagnosed as having breast cancer she will begin to think about life with one or no breasts and will wonder how to go on so diminished. The maimed and asymmetrical body among bodies not so affected will forever be a reminder of the unpredictability of the body, uncertainty about the future and fear of recurrence and death. Prostheses served to hide the perceived lack of symmetry and flawed beauty in social circumstances but the endangered body in conjunction with women's fears were experienced as a secret, private pre-occupation. Women were interviewed two to twenty years following mastectomy and such retrospective data collection may have influenced women's recall and in turn their illness narratives.

Similarly, Goffman (1997) argues that this cultural necessity to disguise and keep secret single-breasted status not only prevents a woman from being 'discredited' but serves as a reminder of living with a stigmatised disease. Normalising appearance in an attempt to regain womanhood and keep illness a secret to avoid stigmatisation has more recently been noted by Vargens and Bertero (2007). This notion is of particular importance when considering the links between the internalisation of stigma, self-blame (Crocker & Quinn, 2000) and low-self-esteem (Else-Quest, LoConte, Schiller, & Shibley Hyde, 2009).

Ethnographic research involving interviews with twenty three cancer survivors demonstrates the implications of presenting the changed body in social

encounters including avoidance by others, perceiving being stared at and being met with specific statements that prevent further dialogue about experiencing cancer (Rasmussen, Hansen & Elverdam, 2010). Only four of the participants in this Danish study had breast cancer, all of whom had undergone surgery though the amalgamation of their data with other cancers and lack of gender specific consideration limits the conclusions that can be drawn.

Nevertheless, in a similar vein Lorde (1985) criticises 'other one-breasted women' for 'hiding behind the mask of prosthesis or the dangerous fantasy of reconstruction' and argues that 'the socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from others' (p. 16) - for the sake of society, so as not to spoil public optimism. Likewise, Broom (2001) views reconstruction as a way of concealing the material traces of cancer treatment. Breast reconstruction is deemed as a means by which women can be aided to rebuild their body image, confidence and self-esteem that has been diminished following breast surgery (e.g. Farrell Yelland, 2000). An investigation of immediate breast reconstruction with silicone prosthesis one year post-surgery in a group of 61 women who had undergone prophylactic mastectomy and 63 women who underwent mastectomy for breast cancer reported that the most important perceived advantage of such reconstructive surgery was not requiring the use of an external breast prosthesis (Contant et al., 2004). Approximately one third of participants were found to have specific complaints regarding the implant including pain and skin tension though 80% of women were satisfied with the surgery. Lower satisfaction was found to be predominantly associated with poor perceived cosmetic outcome, a greater need for information and higher number of specific prosthesis-related complaints. The Dutch study is limited by the use of self-

report measures and the fact that in the UK immediate breast reconstruction is not available to all women with breast cancer. It does, nonetheless, highlight the importance women ascribe to having breasts. Clothing is also a commonly reported reason provided by women for choosing breast reconstruction as opposed to breast prosthesis as women perceive the latter option to limit clothing choices and reduce enjoyment in activities such as swimming and sun-bathing (van Wersch, 2001).

The emphasis on breast prostheses and reconstruction would suggest that breasts are a necessity, however, prostheses cannot perform the material functions of a real breast. As such Broom (2001) argues that reconstructed breasts are for the sexual incitement of others and that public advice describing reconstruction as a means by which a man's anxieties and distress can be reduced implies that the woman should work in accordance with her partners preferences and that pleasing her partner should be a high priority regardless of her own emotions.

The quantity of literature depicting breast cancer and breast reconstruction in a positive light is overwhelming. Farrell Yelland's (2000) book, for example, depicts women's stories of breast cancer with celebrities discussing their reconstruction, always in a positive light, and often describing the new breasts as being better than before. For writers like Broom (2001) the concern is that in masking injuries and always portraying breast cancer in a positive way progress towards less savage treatments and more effective primary prevention may be impeded. Lorde (1985) too contributes to this debate by stating that the emphasis on reconstruction and prosthesis undermines the individual struggles of women to cope with the consequence of the disease and to take control over

their lives after breast surgery. Furthermore, despite a change to women's inner self as a consequence of experiencing breast cancer, reconstruction may provide an opportunity to keep the outer self unchanged thereby requiring less reconstruction of a woman's sense of self (van Wersch, 2001).

The nature of breast cancer can therefore complicate the connection between identity and the body via breasts being seen as a symbol of femininity and sexuality and by influencing a woman's sense of embodiment. 'The body is and is not the self: if they were entirely separate, the mastectomy would not be traumatic; if they were entirely coextensive, it would not be speakable' (Hartman, 2004, p.156). Crouch and McKenzie (2000) argue that treatment decisions are most likely to be influenced by women's feelings and attitudes towards their bodies and the preservation of the integrity of their bodies. What is more, if breast conservation is as important as it seems to most women by implication the loss of a breast can be assumed to be a considerable threat to a woman's embodied identity and self (Crouch and McKenzie, 2000). The following section brings together the notions of self, body, and embodiment in relation to women's experiences of breast cancer.

## **2.5 Self, embodiment and women's experiences of breast cancer**

Qualitative research investigating women's experiences of breast cancer and its meaning has increased in the last decade however it is predominantly focused on pre-determined aspects of women's experiences and applying theoretical models. Analysis of individual's illness stories can provide an insight into experiences of suffering and coping in the context of chronic illness. Frank (1995) developed the concept of illness narratives and proposed three narrative types through which illness experiences are revealed. Frank's (1995) first



category of illness narratives is argued to be the most common form of narrative, restitution. The structure of such a narrative focuses on the move from health to sickness and a return to a previous state of health. It is about moving back and forth from health and illness and focuses on experiences of diagnostic tests and medical regimes. Frank argues that while it can be advantageous to hear stories of a return to good health it can equally be considered to be medicalised and consequently a form of social control, reinforcing the importance of the medical model. The chaos narrative "imagines life never getting better" (1995; p. 97) and tends to lack specific sequencing of timing. These narratives may therefore be difficult to hear though Frank argues it is vital to hear these stories of "wreckage" as they enhance our understanding of the illness experience. The quest narrative depicts illness as being useful and is commonly seen in terms of illness as a "challenge" which gave impetus for change. Frank suggests three sub-types to the quest narrative: memoir whereby events are related simply; manifesto in which illness is reported to be a motivator for social change or action; and automythology where illness reveals fate or destiny (Frank, 1995). The quest narrative may be considered therapeutic or conversely limited depicting movement through illness "as too clean and the transformation too complete, and they implicitly deprecate those who fail to rise out of their own ashes" (Frank, 1995, p.135).

Through interviews with twelve women Thomas-MacLean (2004b) explored experiences of breast cancer in relation to Frank's three narrative types. She found that restitution was most desired by participants and reflected their desire to return to a time of normality. Thomas-MacLean eluded to the prospect that for women with breast cancer full restitution may not be possible particularly given fears of recurrence and that conscious action through the use of

prostheses is needed daily to maintain "normality". Accordingly, the term "reconstruction" was proposed to replace restitution especially given the possibility that some women may not want to return to their prior status. She noted contradictions in women's restitution narratives as they expressed issues pertaining to a changed body yet stated that they had not changed as a person. Chaos narratives occurred most frequently when participants talked about body difficulties and the involvement of other people in their lives and manifested at different times in participants' narratives. The study reported identifying few quest narratives and noted that some women who recalled stories from media quest narratives felt that these missed elements of chaos that represent the true nature of the breast cancer experience.

The application of Frank's narrative types to the narratives of women with breast cancer in the Thomas-MacLean (2004) study revealed limitations in that some women found it difficult to articulate their experience and for one woman Thomas-MacLean reported no emerging narrative type as breast cancer was perceived to be insignificant. The study itself was limited by the sample used including only women who had undergone mastectomy, as opposed to lumpectomy, and included no women who had elected to undergo reconstructive surgery. Moreover, the time since diagnosis ranged from one to twenty four years which may have influenced women's recollections of experience and narrative types.

A meta-synthesis (Bertero & Wilmoth, 2007) of 30 qualitative research reports conducted between 1990 and 2003 with 795 women from the USA, Canada, Australia, the UK, Sweden, Norway and South Korea and Hong Kong, investigated the impact of breast cancer on the self. Methods used by the

included studies were described as qualitative, grounded theory, phenomenology, narrative, content analysis, focus groups and combinations of these methods. Four aspects of the self were found to be affected by a breast cancer diagnosis and its treatment. Firstly, awareness of their own mortality was illustrated through women's descriptions of an overwhelming fear of death which for many women led to a review of their life, seeking meaning in their illness and reordering life's priorities. Living with an uncertain certainty constituted the second finding with women perceiving the only certainty as knowing they would be a "breast cancer patient". Being uncertain about their future quantity and quality of life affected women's sense of self as they tried to regain control of their lives and resume their normal activities.

The third aspect, attachment validation was found to comprise of four elements, the validation of women's own self via emphasising the importance of their existence, which often involved spiritual reflection. Validation from women's significant other that they are loved despite a changed body was considered vital to women's well-being. Validation from family was more complex as women tried to protect loved ones yet wanting to tell the truth though typically felt that their families did not understand their experience. The healthcare team also provided validation by recognising women as individuals and facilitating a role in treatment decision-making. Finally, redefinition of the self in both a physical and mental sense emerged from the review. Women were described as experiencing an altered body image, feeling imperfect due to breast surgery and the other treatments undertaken. Women's sense of self was affected with many studies reporting that women no longer felt complete questioning their womanhood and femininity. Limits to physical functioning additionally led to decreased value of the self.

Bertero and Wilmoth (2007) summarised by concluding that following a breast cancer diagnosis women work to rebuild their lives, incorporating a new outlook and a new sense of self. This review employed measures to maximise the credibility of the data interpretations though some issues are apparent. When describing the process of meta-method via assessment of the primary research papers the authors report finding that five articles were literature reviews and eight were predominantly quantitative in nature but with some qualitative element, one article was a single case and six did not meet the review inclusion criteria. Furthermore, the vast majority of studies were from the USA with only three studies from the UK and content analysis was the most common approach of the included studies potentially limiting the depth of data collected. A number of factors influential in women's experiences were also not reported in the review such as the types of treatment women underwent from the studies and the length of time from diagnosis to data collection.

Helping to address the paucity of UK based research and a lack of longitudinal data collected from the point of diagnosis McCann, Illingworth, Wengstrom and colleagues (2010) conducted an exploration of the experiences of twelve women with breast cancer within the first year following diagnosis using biographical disruption and embodiment to guide analysis. They described the emergence of two key concepts 'Identity transition: moving between health and illness' and 'Making the transition to the future? Living with breast cancer and moving on'. The authors illustrated that women's narratives move towards illness with references to bodily changes such as breast and hair loss and that this altered appearance often led to a disrupted identity and sense of self. As time progressed many of the study participants discussed both difficulties coping with multiple side-effects and with envisaging an end to their experience.

Physical scars and ongoing side-effects from hormonal therapies were believed to contribute to this resulting in breast cancer having a prevailing effect in women's lives. The paper, however, reports few methodological details lacking information pertaining to the timing of the interviews during the first year and the type of surgery experienced by the twelve women. A highly structured and framed approach to data collection and analysis may have further served to limit the exploration of the meanings of breast cancer to the individual women interviewed. This is particularly so given that this was part of a larger study into a number of cancer experiences and accordingly a generalised interview schedule was used.

A second UK based longitudinal study (Tighe, Molassiotis, Morris & Richardson, 2011) did focus on women's experiences of breast cancer and aimed to explore issues relating to symptoms, treatments and its effects. Interviews were conducted with ten women, the majority with early stage breast cancer, over the course of a year (39 interviews in total). The study adopted a thematic narrative approach using the 'cancer journey' as a device to aid 'storytelling', essentially data collection from the earliest possible point from diagnosis through to living with and beyond cancer treatment. All women were undergoing active treatment involving combinations of chemotherapy, radiotherapy, endocrine therapy, with eight participants having undergone surgery. The core themes said to have been identified across all cases were symptom experience, coping and meaning, and relationships, however the authors note that these were personal to each sufferer. Rather than providing an overview of these themes the paper presents findings from only four women's experiences representing the overwhelming aspects of personal suffering for these individuals. The findings focus on the symptom experience though the paper concluded that women feel

unprepared for the impact on their abilities to cope. Furthermore, unmet needs for fatigue management, adaptation to hair loss and disfigurement, and for sexual health and relationship counselling were identified. Finally, the study concluded that women's narratives show a cancer journey that was not static but an unstable process of despair and renewal in the context of their inter-personal relationships and inter-personal existential crises.

While the two aforementioned studies (McCann et al., 2010; Tighe et al., 2011) adopt a longitudinal perspective, in contrast to the present research, a focus on specific aspects of the illness experience (transitions and the symptom experience) limits the insight gained into women's experiences of breast cancer and the meaning of issues relevant to women over time. Nonetheless, in summary, it can be surmised that breast cancer may impact upon women's identities, sense of self, and embodiment to varying degrees given changes to, and perceptions of, the body and ways of being in the world.

## **2.6 Chapter summary**

Despite the complexities of defining the multifaceted concepts of self and identity, being diagnosed with a life-threatening illness and specifically one underpinned with feminine connotations undeniably challenges a woman's sense of who they are and how they view their body. It alters how they view themselves in relation to others and in turn influences their interactions. With regards to embodiment, in accordance with the aforementioned model of Morse (1997), women revalue their lives and their focus may shift from the outer body to the inner person. In doing so they become more embodied in 'what they are' and less embodied in what they physically can do and they incorporate any

physical changes into a new identity and learn to 'live with the altered self'. However, adaptation to bodily changes and a new self-concept depends on the physical response of a woman's body as well as her emotional well-being. Psychological adjustment to breast cancer is discussed in the forthcoming chapter wherein theories of stress and coping are reviewed and the impacts of coping styles on women's well-being are considered.

## **CHAPTER 3: STRESS AND COPING WITH THE BREAST CANCER EXPERIENCE**

### **3.1 Introduction**

The psychological impact of receiving a diagnosis of breast cancer and an exploration of how women cope with the illness are the focus of review throughout this chapter. Models of stress and coping are firstly described in order to provide a theoretical underpinning to which women's experiences of breast cancer may be applied. Research investigating women's adoption of a range of coping strategies and the psychological issues previously identified as being faced by women during their experience of breast cancer are evaluated.

### **3.2 Theories of stress and coping**

A number of theories of stress and coping have been applied to illness and specifically to breast cancer and consequently may be of relevance to the present study. Stressors can be defined as "threats, demands, or structural constraints that, by the very fact of their occurrence or existence, call into question the operating integrity of the organism" (Wheaton, 1997; p.46). This description would seem to acknowledge that stressors may have biological, personal and social components.

#### ***3.2.1 Physiological models of stress***

One of the earliest models of stress developed by Canon (1932 as cited in Ogden, 2007) proposed that external threats elicit a 'fight or flight' response denoted by physiological changes of increased activity rate and arousal. In times of emergency the instinctive response to the external stressor results in



an individual seeking to escape from or defend themselves from the threatening situation. However, the re-classification of breast cancer to a chronic illness (Tritter & Calnan, 2002) may limit the applicability of the fight or flight model to breast cancer. While Selye's (1950) general adaptation syndrome is also based on physiological reactions to stress it does consider stress in the longer-term. The model consists of three main stages, 'alarm' which occurs as soon as the individual is faced with the stressful situation and refers to an increase in activity of bodily processes. If the stressor is not removed the individual enters the second stage, 'resistance', during which the individual attempts to cope and reverse the effects of the first 'alarm' stage. The final stage 'exhaustion' is reached following repeated exposure to the stressful situation leading to bodily resources e.g. sugars, running out. Selye purports that such deficiencies cause physiological disorders and potentially death. These models, however, view stress as an automatic response to an external stressor neglecting psychological factors and the potential for an active interaction between the individual and the stressor rather than simply a passive response. Furthermore, the literature exploring the parameters of these models is predominantly conducted on animals and women are underrepresented in human stress studies.

Proposed as an alternative to Canon's (1932) theory of fight or flight, the "tend-and-befriend" biobehavioural model (Taylor, Klein, Lewis, Gruenewald, Gurung & Updegraff, 2000) describes women's responses to stress as having evolved as a result of differential parental investment. Specifically, it is theorised that females respond to stress through a tending pattern which involves nurturing activities designed to protect the self and offspring, and by creating and maintaining social networks (befriending) that reduce risk. Taylor et al. (2000)

contend that the model is based on the attachment-caregiving system, and that neuroendocrine responses in conjunction with female reproductive hormones underpin women's pattern of stress reactions. While this theory is limited due to the combined observations from human and animal literature used by the authors as well as a lack of consideration of the nature of the stressor, the focus on female stress responses may have applicability to the present study.

### ***3.2.2 Psychological models of stress***

The role for a psychological dimension in stress responses was introduced by Lazarus in the late 1970s in his transactional model of stress and theory of appraisal (e.g. Lazarus & Folkman, 1987). The model states that if an individual perceives an event as stressful a stress response is elicited. Individual differences are therefore paramount in this theory with primary appraisals, those made initially by the individual, being viewed as either irrelevant, benign and positive, or harmful and negative. During secondary appraisal the pros and cons of the individuals coping strategies are evaluated.

In relation to cancer there is a growing body of literature on the effects of stress on cancer relevant biological processes (e.g. Antoni et al., 2006) and recent reviews present data to suggest that psychological intervention can influence stress-tumour pathways (McGregor & Antoni, 2009). This highlights the importance of adaptation to the stressful aspects of cancer which can vary along the disease trajectory from diagnosis to awaiting and undergoing treatment and on to treatment completion, medical follow-up and survivorship (Knobf, 2011). Research with 232 women with newly diagnosed breast cancer indicates that such adaptation is twofold (Compas, Beckjord, Agocha et al., 2006). This begins with involuntary automatic responses to the stress of the

diagnosis and treatment illustrated by uncontrollable, intrusive thoughts or heightened psychological reactivity. Secondly, there are controlled voluntary responses represented by goal directed efforts to cope with the experience. Accordingly, in exploring women's longitudinal experiences of breast cancer, the present study may provide greater insight into women's perceptions of, and responses to, stress as well as coping mechanisms utilised throughout the first year following diagnosis.

### ***3.2.3 Theories of coping***

Cognitive theories of coping posit that major life stressors challenge an individual's view of the world and sense of self due to the discrepancy elicited between the information inherent in the stressor and people's positively skewed expectations about the world (Lepore, 2001 as cited in Kernan & Lepore, 2009). The belief that 'bad things do not happen to good people' (Kernan & Lepore, 2009; p. 1177) is challenged when a 'good' person gets cancer and it is this psychological discord that leads to distress and an individual utilising coping efforts to resolve the discrepancy (Kernan & Lepore, 2009). On the basis of Lazarus' theory, the stress and coping paradigm of Lazarus and Folkman (1984) denotes that the greater the perceived threat and less able an individual feels in relation to coping, the greater the stress response. The model proposes that coping strategies can be classified as 'problem-focused coping' referring to behaviour directed at solving the problem and 'emotion-focused coping' which is behaviour directed at changing emotional reactions to the problem. This latter element covers defensive and avoidance strategies. A further classification can be made here between active and passive strategies (Carrico et al., 2006). Avoidance is otherwise termed a passive strategy and relates to an individual's

attempts to avoid rather than confront the source of distress, whereas active coping efforts are aimed at facing a problem directly and determining viable solutions to reduce the effect of the stressor (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). Coping is viewed as being independent of outcome. In line with the "goodness of fit" principle emphasising the importance of fit between coping and context, problem-focused coping is said to fit controllable situations compared to emotion-focused coping which fits uncontrollable ones (Folkman, Schaefer & Lazarus, 1979). It is nevertheless argued that this general principle does not cover the entire range of strategies that could be effective for coping with uncontrollable stressors (Benyamini, 2009) such as a breast cancer diagnosis.

Alternatively, self-regulation models attempt to explain how individuals cope with stressors and deem people to be problem-solvers motivated by goals, gathering information which is integrated with prior knowledge in order to form a subjective assessment of their status, which in turn guides their coping efforts (Benyamini, 2009). The most prominent theory of self-regulation in the health and illness literature is Leventhal's Common-Sense Model (CSM; Leventhal, Meyer & Nerenz, 1980). This proposes that when an individual encounters a health problem a process is initiated at both cognitive and emotional levels which work in parallel to firstly form illness representations by drawing upon current somatic symptoms and comparing these to previous illness experiences and external information. Subsequently, coping procedures are executed aimed at managing the stressor and strategies are implemented to address its emotional representation. Finally, an individual is said to appraise their status based on their coping efforts and this steers future actions.

If an individual perceives the outcome to be unsatisfactory this can either lead to changing their initial representations and coping strategies or to retain their initial representations but change their methods of coping. Furthermore, the model purports that there are higher level abstract representations and lower level concrete representations, each level with specific coping strategies. As an example, at an abstract level cancer worries may lead to greater attention to bodily changes while at a concrete level identification of a specific symptom may lead the individual to seek care (Benyamini, 2009). While the process should be the same for all individuals the content will differ at the level of the stressor and of the self, given that the self-regulation process is said to be embedded within the self, as well as the social and cultural context ascribed to the illness. The longitudinal nature of the present study may be particularly beneficial in facilitating exploration of variation in coping strategies over time and the implications for women's breast health.

The relationship between stress and illness is complex and can be mediated by a number of factors including coping styles, social support, notions of control, personality and lifestyle. Moreover, stress can affect an individual in both psychological and physiological terms and coping responses can be multifaceted. An Australian study aiming to identify psychosocial concerns and needs explored coping via seven focus groups involving thirty four individuals including women diagnosed with breast cancer within the last year, oncology nurses, and volunteers working with cancer patients, the majority of whom had experienced breast cancer (Beatty, Oxlad, Koczwara & Wade, 2008). Thematic analysis revealed consistency across the three participant groups in relation to five themes the first of which was coping with side-effects including fatigue, insomnia, lymphoedema, and malnutrition. The second theme related to coping

with self-concept change incorporating coming to terms with an altered body image and changed roles within the home. Stress and adjustment reactions were commonly reported in relation to diagnosis, treatment and treatment completion with women citing distress, depression and isolation. Managing the impact on others, relationship and intimacy issues, and managing the emotional reactions of others in their social networks constituted the fourth theme. Finally, theme five, termed survival and growth, encompassed issues of coping with uncertainty and mortality. It should be noted that the three specific concerns of uncertainty of treatment success, coping with fatigue and maintaining a 'game face' were not cited by the nurse participant group. The five themes elicited a number of needs women perceived would aid their ability to cope with breast cancer including wanting to increase bodily self-esteem, develop a non-breast cancer identity and explore the positives of diagnosis. Focusing on gaining control through exercising personal choice, finding opportunities for emotional expression, filtering information to minimise feeling overwhelmed and a need to maintain normality and gain positivity were also highlighted. The study was limited by the small self-selecting sample which impacts upon the representativeness of the views recorded. Moreover, the issue of recall bias was acknowledged with participants in the volunteer group responding with self-referential observations, commenting on longer-term experiences rather than the period of diagnosis and treatment. The present research overcomes the limitation of retrospective data and lack of focus on the healthcare trajectory by exploring women's experiences at time-points from post-surgery to early follow-up.

### **3.3 Coping and breast cancer**

There is a vast body of literature pertaining to breast cancer and coping styles and their impact on various outcomes. This section draws on the most influential and recent empirical research to review the most prevalent coping strategies and their associated impact on psychological outcomes.

#### ***3.3.1 Coping strategies***

The coping strategies utilised by women impact on their adaptation and response to breast cancer (Doumit, Huijer, Kelley et al., 2010). Specifically, the strategies used during the diagnostic phase have been found to be indicators of psychological adjustment after surgery (e.g. Jadoulle, Rokbani, Ogez et al., 2006).

Through a six-month prospective correlation study Jadoulle and colleagues (2006) demonstrated that anxiety and depression scores six months after surgery were associated with scores obtained at diagnosis observing a decrease in anxiety levels and stability in mood at the six month time point. Similarly, coping scores recorded during the chronic phase (six months post-surgery) were related to those obtained at the acute illness phase (in hospital, the day before surgery). A decrease in the use of instrumental strategies (i.e. active problem-focused strategies such as information-seeking) over time was noted while distraction and palliative strategies (i.e. self-help responses to alleviate the unpleasantness of the situation such as getting rest) remained stable over time. Moreover, analysis of the relationships between mood and coping suggests that these palliative coping strategies were often detrimental at six months post diagnosis while distraction had a protective effect on mood at both time points. This study conducted in Belgium utilised translated self-report

measures that were not validated in French and while 151 women completed time one assessment only 107 of these women did so at time two. Selection bias and lack of control for cancer grade and treatment type were further methodological issues limiting the inferences that can be drawn from the study results.

However, the coping literature predominantly suggests that active coping strategies produce more favourable outcomes compared to passive coping strategies such as avoidance (Kim, Han, Shaw, McTavish & Gustafson, 2010). The strategy of avoidance can extend to communication which can have negative consequences for cancer patients (Donovan-Kicken & Caughlin, 2011). Avoiding talking about breast cancer can impede communication with others thereby limiting social support which in turn can heighten psychological distress (Harrison, McGuire & Pitceathly, 1995; Northouse, Laten & Reddy, 1995). This strategy may also influence women's cognitions who without communication may be more likely to engage in denial or self-blame (Carver, 1997) and limit gaining perspective and moving towards acceptance of their illness (Pennebaker, 1997).

In a quantitative study by Donovan-Kicken and Caughlin (2011) with 140 American women who were undergoing treatment or had recently completed treatment for breast cancer, an online self-guided questionnaire was used to examine coping behaviours and topic avoidance. Not only was topic avoidance associated with higher levels of anxiety and depression but emotional support and self-blame were found to be strong mediators of topic avoidance and psychological distress. Furthermore, acceptance mediated the relationship between topic avoidance and depression with lower levels of acceptance



conferring greater avoidance and depression. The authors suggest that topic avoidance may influence coping options that people recognise and pursue. The statistical models used, however, only imply causality and it is plausible that the relationship between these factors works the other way with depression leading to poor coping and avoidance.

Spending time with others can nevertheless be helpful not only as emotional support but as a means of distraction. In a qualitative study investigating coping with cancer in a sample of seven Chinese cancer patients (Chen & Chang, 2012) interviews were analysed in accordance with grounded theory. A core concept termed "balance process of life fluctuation" was identified encompassing three themes: negative feelings, self-adjustment and self reinterpretation. Negative feelings and emotions were commonly reported from diagnosis to treatment completion and were related to mental distress and loss of physical control. Participants were reported to have found ways to adjust personal beliefs (e.g. self-encouragement, acceptance) and lifestyles including work schedules, workload and diet with effective coping strategies leading to a greater sense of meaning in life and a positive future perspective. Positive self-reinterpretation was found to be an effective strategy for cancer patients in coping with their illness. However, only five of the seven participants had breast cancer and disease specific differences were not established. The lack of long-term follow-up further limits the study findings.

A previous Chinese study by Li and Lambert (2007) found that in one hundred women with newly diagnosed breast cancer, planning and self-distraction were prominent coping strategies in addition to positive reframing. Positive cognitive restructuring or reframing is an active strategy whereby individuals attempt to

view things in a more positive light. Women have described this as the 'best' strategy for coping with fear and uncertainty about the future (Manuel et al., 2007). Factors contributing to positive thinking include being physically fit, having good humour and positive self-talk (Drageset et al., 2009). Making changes, social support, physical activity, medication and rest are also well documented active strategies (Manuel et al., 2007). However, Manuel and colleagues (2007) noted that different strategies are best suited to different aspects of women's breast cancer experience reporting, for example, that social support was most helpful for dealing with anger or depression while positive cognitive restructuring was more beneficial for managing future concerns.

Religious approaches to coping were among the most frequently reported strategies by cancer patients in several studies (e.g. Taleghani et al., 2006; Zwingmann, Muller, Korber & Murken, 2008). Having trust that 'God' was in control of their illness women became stronger believers in an after-life concept, less afraid of death (Shaw et al., 2007) and their faith led to hope and a need to cope with whatever 'God' had planned for them (Doumit et al., 2010). Moreover, in their qualitative study exploring ten Lebanese women's experiences of coping with breast cancer Doumit and colleagues (2010) stated that another prominent method of coping was to make comparisons to acceptable chronic illnesses, predominantly diabetes which does not hold the same stigmatising connotations as breast cancer in Lebanese culture. However, the study was constrained by its small sample, the wide range of breast cancer experience held by participants (up to nine years post diagnosis), specific sample characteristics and limited applicability to other cultures.

A Norwegian descriptive qualitative study of twenty one women with newly diagnosed breast cancer explored coping strategies between the time of diagnosis and surgery (Drageset, Lindstrom & Underlid, 2009). A series of opposing means of coping were uncovered including information seeking versus a step-by-step approach to knowledge acquisition. Information seeking has been documented as a positive coping strategy among women with breast cancer (e.g. Rees & Bath, 2000) but the preference of some women for the use of a step-by-step approach enabled them to face the realities of their diagnosis gradually. This was concluded as facilitating the process of acceptance, a means of preparing for what was to come and ensured a focus on facts rather than potential occurrences. The authors noted that this coping strategy gave women a sense of control over a situation that they deemed as being out of their control and kept anxiety at a manageable level. The second coping strategy reported was classified as business as usual versus enjoying life. Maintaining a normal life was viewed as important while awaiting surgery as it led to some control over life, strengthened self-confidence and reduced anxiety. Living as usual has previously been found to be a meaningful way of coping by Landmark and Wahl (2002).

Women in the Drageset et al. (2009) research study tried not to be overwhelmed by their emotional reactions and dealt with their emotions by either displaying expressive emotions such as crying which helped to stop feelings of depersonalisation or by holding back with the aim of avoiding feelings of weakness and self-pity which were seen as reducing their ability to cope. This is an important finding as the expression of emotional feelings after diagnosis has been linked to better survival rates (Reynolds, Hurley, Torres, Jackson, Boyd & Chen, 2000). Indeed, emotional suppression, particularly

anger suppression, characterised by a conscious effort to inhibit the expressive elements of emotional experiences, predicted higher reports of symptoms relating to immune function and cardiovascular arousal and with appraisals of poorer coping during chemotherapy for breast cancer (Schlatter & Cameron, 2010). Another key finding was that irrespective of how positive women tried to be, negative thoughts and anxieties regarding metastases and death were evident and led some women to mentally prepare for the worst. According to Folkman and Moskowitz (2004) this can represent future-oriented coping which reflects efforts to save strength to deal with future events.

While the Drageset et al. (2009) study conveys several findings of importance in the field it is limited, as are many similar studies, by the specific time span involved (e.g. between diagnosis and surgery). However, acceptance at diagnosis has been found to be a predictor of better adjustment and well-being during the first year following diagnosis. A quantitative study with a sample of 72 Greek women with recently diagnosed breast cancer investigated coping efforts and distress the day before surgery, three days post-surgery and three months after surgery. The findings showed that the use of multiple coping strategies negatively predicted distress (i.e. less reported by women) (Roussi, Krikeli, Hatzidimitriou & Koutri, 2007). The study additionally reported that acceptance and humour were negatively related to distress at all three time points however denial and emotional expression were positively associated immediately post-surgery and three months later. Further analysis revealed that women who used emotion-focused engagement coping (acceptance or emotional expression) at pre-surgery experienced less distress three months later than women who did not engage in emotion-focused coping. The use of a specific sample of Greek women with low socio-economic status and low educational levels limits the

generalisability of the findings. In addition, the measurement instrument used asked women how they coped with breast cancer in general and did not differentiate between different aspects of the illness. Finally, as follow-up was undertaken after only three months and accordingly women's experiences of coping in the longer term were not ascertained.

A longer term study assessed women's coping processes and adjustment during the year following diagnosis in seventy women with early stage breast cancer (Stanton, Danoff-Burg & Huggins, 2002). Acceptance at diagnosis was found to predict positive adjustment over time whereas avoidance-oriented coping predicted greater fear of cancer recurrence. Coping through religion was reported as being more effective for women who were less hopeful and younger age predicted greater distress one year on. The use of a homogenous sample from the USA, the use of multiple self-report questionnaires and the design not allowing for causal inference to be established limits the conclusions that can be reached. However, Hack and Degner (2004) provided support for these findings recording that women who respond to a breast cancer diagnosis with passive acceptance and resignation were at significant risk of poor long-term psychological adjustment.

Adopting a different methodology one large scale longitudinal UK research project examined the meaning of illness for women with breast cancer at the time of diagnosis and approximately twenty one months later (Luker, Beaver, Leinster & Owens, 1996). One hundred and five women were interviewed and after being shown a series of cards depicting eight different coping strategies were asked to choose the card that best represented their experience at that time. Descriptive statistics were used to ascertain the distribution of preferences

and qualitative analysis was undertaken on the comments women provided explaining their choice. Breast cancer was reported to be a challenge for the majority of women at both time points with comments expressing the need for positivity, emphasising change in their lives and giving them an appreciation of life and reconsideration of priorities. The authors highlight that identifying women's individual coping strategies may facilitate effective tailoring of psychosocial support for women with breast cancer. The paper does not present any demographic or treatment details and the descriptive nature of the paper restricts the conclusions that can be drawn.

A recent review of the literature on coping with a diagnosis of breast cancer (Al-Azri, Al-Awisi & Al-Moundhri, 2009) summarised factors that can influence coping strategies. Demographic characteristics, educational level, positive thinking and psychosocial support were identified as of importance in determining women's methods of coping. Educated women were better at engaging in positive coping strategies and women who were less educated, single, divorced, or widowed had a greater use of cognitive defences such as denial (Drageset & Lindstrom, 2005).

### **3.3.2 Social support**

Reference to social support is common in the stress and coping literature and refers to support received (e.g. emotional, informational) or the sources of support (friends, family, healthcare professionals) that enhance recipients self-esteem or provide stress related interpersonal aid (Dumont & Provost, 1999 as cited in Kim et al., 2010). The most influential theories regarding social support state that support reduces the effects of stressful events as the supportive actions of others facilitate coping (Thoits, 1986) or that a belief that support is

available if needed leads to an appraisal of events as less stressful (e.g. Lakey & Cohen, 2000).

Two models dominate the literature concerning the effects of social support on alleviating stress, the main effects model and the stress buffering model. The main effects model proposes that social support is beneficial irrespective of stress level while the stress buffering model predicts that social support holds less value when stress levels are low given there is less to buffer (e.g. Cohen & Wills, 1985). Support has been found for both models through the adoption of different measures of social support. Support for the main effects model has been found when the number of people in a person's network is measured, however support for a buffering model has been established when perceived quality and appropriateness of support are measured. In the context of early stage breast cancer multi-level analysis of ninety five women's daily reports of emotional and physical experience and factors relating to spousal support elicited results in accordance with a stress buffering effect for social concerns (Gremore, Baucom, Porter, Kirby, Atkins & Keefe, 2011). However a reverse stress buffering effect was established for emotional and physical concerns whereby the buffering effect of spousal support was attenuated when high levels of breast cancer related emotional and physical concern were reached.

Social support has been reported to not only reduce the stress of a breast cancer diagnosis but to also improve emotional well-being in women with breast cancer (e.g. Holland & Holahan, 2003). The final theme ascertained from the phenomenological qualitative study by Doumit and colleagues (2010), as discussed previously, was the impact of positive social support from family and work colleagues on the coping process. This was considered to help with

acceptance and gave women encouragement to cope. Holland and Holahan (2003) found that breast cancer patients who perceived high levels of social support made greater use of positive reappraisal and planned problem-solving as their coping strategies which led to these higher levels of emotional well-being. More recently, Kim and colleagues (2010) found data from 231 women to support a mediation model of emotional well-being whereby breast cancer patient's perceptions of how much social support they receive from others influenced their choice of coping strategies and in turn their well-being. This is in contrast to a moderation model which proposes an interaction between social support and coping strategies in affecting psychological well-being. While the measurement instruments used had recognised reliability and validity this study conducted in the USA is limited given the cross-sectional research design thereby not providing the direction of causality.

Nonetheless, a UK based qualitative longitudinal study also reported that close interpersonal relationships were core mediating factors in how individuals, including twelve women with breast cancer, experienced their illness (Illingworth, Forbat, Hubbard & Kearney, 2010). Over the course of the twelve month study period relationships were found to be central even prior to diagnosis. Interaction and debate between partners often instigated a visit to the GP for symptom investigation and the supportive environment created by partners and close family members meant any reluctance to seek help was overcome. Partners were additionally identified as playing a role in treatment decision-making with some partners assuming a dominant role. Partners' awareness and interpretation of the information received was particularly crucial in the decision-making process. Cancer was reported to impact both the person with the disease and their partner, which Illingworth et al. (2010) referred to as



"joint ownership" (p. 26) with cancer leading to the renegotiation of roles and tasks in the relationship and difficulties making future plans. The lack of focus on relationships within the context of breast cancer somewhat limits these study findings given previous discussions on the uniqueness of the disease.

Moreover, women may have difficulty relating to people in their social network about their illness which can put strain on their relationships (Gremore et al., 2011). Unsupportive negative behaviours are often reported by cancer patients including problem minimising, forced cheerfulness and insensitive comments (e.g. Dunkel-Schetter, 1984). Such undesired support may lead women to, for instance, view their partners as insensitive or patronising (Dehle, Larsen & Landers, 2001) and is associated with poor psychosocial adjustment to breast cancer (Manne, Sherman, Ross, Ostroff, Heyman & Fox, 2004). Through an exploration of the suffering experiences of seventeen women with breast cancer and their significant others a qualitative case study elicited an overall theme the authors termed 'a field of force' (Arman, Rehnsfeldt, Lindholm & Hamrin, 2002). This metaphor represented women's experience of changed lives, perspectives and relationships as a result of breast cancer. A sub-theme 'doubled suffering' referred to how women's suffering was perceived to increase when it was concealed or unspoken. This was found to be undertaken by women themselves to protect others and women were denied suffering by those around them including the health care system which treated their body neglecting their suffering. Relief from suffering came from confidantes who gave the woman strength and courage though women often suffered in silence. A breast cancer diagnosis resulted in existential questions pertaining to the meaning of life and the possibility of death. Through this process of inner reflection suffering was made more bearable and led to a transformation of the self and greater sense

of embodiment. Like the majority of qualitative studies exploring women's experiences of breast cancer Arman et al. (2002) reported a wide ranging time since diagnosis, from one year to just under five years and the stage of breast cancer differed among the sample, including some women with metastases. Furthermore, participants were from Sweden and Finland limiting the applicability to the UK given differences in the healthcare systems.

The complexities of providing social support to a relative with breast cancer has been underlined by a recent cross-sectional mail survey of seventy two breast cancer patients and their relatives' psychosocial needs (Schmid-Buchi, Halfens, Dassen & van den Borne, 2011). This Swiss study reported that relatives were found to have higher levels of anxiety (25.0% vs. 22.2%), depression (12.5% vs. 8.3%) and distress (40% vs. 34%) than patients. Younger age, having higher levels of depression and having a disease themselves were associated with relatives' need for help. The cross-sectional design, use of numerous self-report measures and low response rate limits the study findings and does not allow for an assessment of change over time. Furthermore, not all of the relatives questioned lived with the patient and the majority of patients had undergone breast conserving surgery with varying combinations of adjuvant therapy and accordingly differing treatment modalities may influence relatives' perceptions and experiences.

The importance of support from healthcare professionals can additionally be highlighted via a study which aimed to categorise the psychosocial needs of women with breast cancer specifically in relation to healthcare system (Lilliehom, Hamberg, Kero & Salander, 2010). This Swedish study further sought to synthesise the identified needs in a model using grounded theory.

Seventy one women younger than 60 years who were treated with radiotherapy were interviewed three or four times over an 18-24 month period. The emerging core category was 'admission into a helping plan' comprising the overlapping categories of needs: 'access', 'information', 'treatment' and 'how approached'. The authors contextualised their findings in relation to attachment theory denoting that in times of stress people seek a 'safe haven' to attach to, in this instance, a helping plan through which breast cancer patients seek to be admitted into a supportive system and well thought out plan of care. The paper concluded that such a helping plan is created by easy access, continuously adapted information, continuity and competence in treatment, respect and commitment from healthcare professionals delivered in a positive atmosphere. The strengths of this research included the large sample size for a qualitative study and the use of repeated interviews. However while all women were being treated with radiotherapy they had also undergone a variety of combinations of treatments including mastectomy, breast conserving surgery, chemotherapy and endocrine therapy and therefore the specificity for an inclusion criteria of completing radiotherapy is puzzling particularly when findings were not discussed in these terms. Furthermore, undergoing different treatment modalities may influence women's experience of the healthcare system and the professionals supporting their care.

### **3.4 Psychological well-being and breast cancer**

Undoubtedly, throughout their breast cancer experience women face a multitude of stressors, navigating the complexities of the medical environment while adapting to a cancer diagnosis and treatment. Women with breast cancer are frequently reported as suffering from decreased physical and social

functioning, uncertainty, and anxiety and depression, all of which may influence quality of life (Salonen, Kellokumpu-Lehtinen, Tarkka, Koivisto, & Kaunonen, 2010).

A recent review of research focusing on the impact of a breast cancer diagnosis advised that women were at risk of developing psychological morbidities, sexual and body image problems as well as an overall decrease in quality of life (Al-Azri et al., 2009). However, only two of the forty five retrieved articles were conducted in the UK with the overwhelming majority of studies being located in the USA followed by Canada and Norway respectively. Twenty nine of the studies were described as quantitative including the two UK pieces of research, fourteen were qualitative and two were mixed methods. This highlights the relative paucity of qualitative research exploring aspects of breast cancer care in the UK.

During the first year following diagnosis women often demonstrated considerable psychological distress (e.g. Glanz & Lerman, 1992) which can be influenced by psychological traits such as coping style, trait anxiety, emotional suppression and optimism (Ando et al., 2011). Furthermore, a number of factors have been identified to increase psychological distress including financial problems (Golden-Kreutz & Anderson, 2004), educational level and marital status (Carver et al., 2005) and personal psychiatric history and level of social support (Grassi, Malacarne, Maestri & Ramelli, 1997). However, many studies investigating the risk of psychological distress have adopted measures of the number of life events combining both positive and negative events. This has been criticised given that negatively perceived life changes have been shown to

influence psychological distress to a greater extent than positive life changes among patients with breast complaints (Ando et al., 2009).

Fann et al. (2008) noted that many women experienced "normal distress" but that there is a subset of women who experienced a major depression. In their review of epidemiology and treatment for major depression following a breast cancer diagnosis they argued that there are a lack of studies on this topic with the few existing studies lacking replicability. They proposed that major depression is frequent yet unrecognised and under-treated among breast cancer patients which can amplify women's physical symptoms, increase functional impairment and hinder treatment adherence.

One large scale survey of 2595 women living in the USA investigated predictors of depression (Bardwell et al., 2006). The results suggest that depressive symptoms are not associated with objective cancer-related factors including treatment type, cancer stage and time since diagnosis, but are strongly associated with subjective psychological variables. Stressful life events, ambivalence over expressing negative emotions, less optimism, poor social functioning and disturbed sleep were associated with greater risk for depressive symptoms. The paper also reported that the prevalence rates observed in the study sample as comparable to the general population strengthening the finding that depression has little to do with breast cancer itself. The study was described as demographically representative of women with breast cancer however the use of cross-sectional data means causality cannot be determined. Furthermore, the measure used to assess depression has been criticised for not discriminating individuals who meet the criteria for mood disorder.

Mood disturbance has been found to be the most significant predictor of cancer-related fatigue before, during and after adjuvant therapy for breast cancer in the study of Von, Kang and Carpenter (2008) who analysed questionnaires and blood samples from 44 women in the USA. Symptoms of anxiety and depression following a breast cancer diagnosis have been found in numerous studies (e.g. Badger et al., 2004; 2007) including a five year observational cohort study of 222 women, aged 60 years or younger, with early breast cancer (Burgess et al., 2005). This UK based research found that nearly half of the sample had depression, anxiety or both one year after diagnosis, 25% after two, three or four years and 15% after five years. The authors suggested that during the first year following a breast cancer diagnosis the prevalence of anxiety, depression, or both, is around twice that of the general population. This suggests a need for specialised service provision addressing women's psychological needs during this time. Previous psychological treatment predicted anxiety, depression, or both, in the time around diagnosis and in the longer-term. Lack of an intimate confiding relationship, younger age, and severely stressful non-cancer life experiences were additionally associated with long-term anxiety and depression.

The latter finding supports that of Tjemsland and Soreide (2001) who documented that a cancer diagnosis has been identified as harder to handle when an individual has other personal or family problems. In line with the aforementioned findings of Bardwell and colleagues, the Burgess study (2005) reported that treatment and prognostic factors including tumour size, histology and type of adjuvant therapy were not associated with anxiety or depression at any time. The exclusion criteria of women over 60 years old confines generalisability to the specific demographic group and it is worth emphasising

the caveat that studies assessing the validity of distress screening tools used for detecting depression have found a high rate of false positives (Mitchell, 2007). Consequently, not all individuals who are positively diagnosed are depressed.

One of the few studies utilising a different methodology to investigate depression, anxiety and quality of life explored the meaning of breast cancer via a cross-sectional survey of 1012 Canadian women (Degner, Hack, O'Neil and Kristjanson, 2003). The research reported that the majority of women (57.4%) indicated "challenge" or "value" (27.6%) as being most representative of their experience and that fewer women chose "enemy" (7.6%) or "irreparable loss" (3.9%). Subsequent follow up of 205 women three years later identified that of those women who had chosen "challenge" or "value" 78.9% did so again and women who had ascribed a negative meaning to their illness reported significantly higher levels of anxiety and depression and poorer quality of life than those women who had chosen a positive representation. However, measures of depression, anxiety and quality of life were not undertaken in the primary study which also recruited women from varying time points in the healthcare trajectory. The two samples also differed in terms of demographic characteristics and disease status which may have influenced the results obtained.

While the suitability of a quantitative measurement of a personal perception is debated (e.g. Gill & Feinstein, 1994), quality of life measures can provide information about an individual's responses to illness and treatment. As in the aforementioned study by Burgess and colleagues younger women, chiefly those under 55 years, have been found to fare worse in relation to quality of life (e.g.

Salonen, Tarkka, Kellokumpu-Lehtinen, Astedt-Kurki, Luukkaala & Kaunonen, 2009). They often contend with a series of different issues compared to older women, for example, having dependent children, concerns about premature menopause and fertility loss, sexuality and career concerns (e.g. Andrykowski et al., 2000). The term quality of life has lost some favour among some researchers and is now frequently termed patient reported outcomes (Garcia et al., 2007). These outcomes may measure parameters related to patient's health status and perception of treatment effects including quality of life and symptom severity typically based on self-report measures (Efficace, Novik, Vignetti, Mandelli & Cleeland, 2007).

The negative effect of chemotherapy on quality of life has also been reported resulting in decreased activity and social participation, more physical symptoms and lower general well-being (Turgay, Khorshid & Eser, 2008). Changes in women's physical and psychosocial well-being as a result of the combined effects of surgery and oncology treatments can additionally influence women's quality of life beyond treatments. However, in the longer-term Engel, Kerr, Schlessinger-Raab, Sauer and Holzel (2004) reported improvements over four years in emotional and social functioning with decreases in fatigue, nausea, future health worries and pain and increases in global quality of life scores after three years. While this is an encouraging finding it equally suggests that breast cancer may have negative physical and psychological consequences for women during the first year in particular when active treatment is undertaken but also that the effects may extend to several years post diagnosis.

Studies on well-being, distress and adjustment are typically limited by the dichotomising of scores in case-based analyses. This grouping of patients on



the basis of whether they score above or below a cut off on the psychological outcome measure can exaggerate small differences between participants and create variability that is not representative of the sample (Millar, Purushotham, McLatchie, George & Murray, 2005). Research into distress and breast cancer has a tendency to focus on specific meaningful illness-related phases and such studies do not take into account that the timing of events often differs for individual women depending upon the number of surgeries required and type of adjuvant treatment(s). The latter issues are of particular significance when considering longitudinal studies as investigations on course of distress are therefore difficult to interpret.

These issues were considered in the design of a recent investigation into the patterns of change in distress among women with breast cancer (Henselmans, Helgeson, Seltman, de Vries, Sanderman & Ranchor, 2010). Measures were administered at time points linked to events rather than, for example, time since diagnosis. The sample of 171 women in the Netherlands, were younger than 75 years and treated with adjuvant therapy (e.g. chemotherapy or radiotherapy). Four trajectories of distress were identified, firstly, a group that experienced no distress (36.3%), a second group showed a pattern of recovery experiencing distress only in the active treatment phase (33.3%), a group that experienced distress in the re-entry (the transition to survivorship) and survivorship phase (15.2%), and a group that experienced chronic distress (15.2%). Consequently, the majority of patients were not identified as being distressed or could be defined as distressed only on a temporary basis while others remained distressed from diagnosis to six months after treatment completion.

Participants experiencing no distress reported significantly fewer complaints resulting from adjuvant therapy. Personal characteristics unlike demographic and objective medical characteristics, had a significant effect on group membership as women with a lower sense of mastery, less optimism, and higher scores on neuroticism were more frequently found in the recovery and chronic groups compared to the no distress group. Nevertheless, the results must be interpreted with some caution as the study authors admit to having data suggesting that participants who were excluded from analysis due to a considerable amount of missing data may have been more distressed than the included participants. What is more, the sample sizes of the four groups that emerged from the modelling analysis were small, decreasing power and in turn leading the authors to report the analysis of predictive variables to be exploratory. Finally, the study focused only on general distress and other variables such as social support were not considered.

In support of the aforementioned longitudinal study a recent literature review of studies relating to quality of life Knopf (2011) reported that research has shown that the majority of breast cancer survivors go on to demonstrate a pattern of recovery after treatment. Furthermore, age, information, social support, degree of symptom distress and unmet psychological needs were found to be key factors influencing quality of life outcomes. The following section considers the notion of control and how this may influence women's experiences of stress and psychological adjustment to breast cancer.

### **3.5 Control**

In general, individuals who experience loss of control over their situation tend to exhibit more stress related problems such as fear, depression, and somatic symptoms than those with a belief in their own ability to influence their situation (Bailey & Clark, 1989). With regards to breast cancer, Mathieson and Stam (1995) found that wanting control over the cancer, treatment, side effects, possible recurrences and a host of other personal issues and yet knowing that complete control was not possible caused anguish for some women. Research findings have additionally shown that women who believed that they could control whether or not it returned were better adjusted psychologically (Taylor, Lichtman & Wood, 1984). In the longer term Barez et al., (2009) in their research study with 101 women with stage I or II breast cancer found a consistent and direct relationship between perceived control and adaptation to illness over five assessment periods during one year post diagnosis, independent of the medical procedures received. Barez et al., (2009) reported that the evolution of distress could be predicted from the initial value and rate of change of perceived control suggesting that this could be used as an early predictor of adjustment to breast cancer. The participants in this Spanish study had a specific type of cancer and a good prognosis which may have influenced the study findings. Similarly, the small sample size limits the statistical conclusions that can be drawn. Moreover, the study authors acknowledge that participants were more distressed than women who chose not to take part and that extraneous variables associated with psychological change over time may have had an effect on the small changes in scores observed.

Discussing the issue of control Moch (1995) describes how a breast cancer diagnosis can lead women to feel "turned over" to the medical profession and

no longer in control of their lives. She asserts that many women feel so vulnerable that they willingly or unwillingly give their bodies over to those, known or unknown, trusted or not trusted, whom they believe or hope will care for them best. Such findings may provide an explanation as to why some women refer treatment decision making to healthcare professionals. From a theoretical perspective, in times of good health, locus of control is balanced between internal and external forces. While internal locus of control relates to the capability of independent decision-making conversely external locus of control pertains to decisions being imposed by external factors (Shaha & Cox, 2003). When faced with uncertainty during illness, deference to healthcare professionals may be undertaken reinforced by their expert status and assumptions that they have patients' best interests in mind (Shaha, Cox, Talman & Kelly, 2008). With these notions supporting an external locus of control, coping with cancer and the uncertainty it brings, may be made more bearable.

However, Moch (1995) refers to women perceiving themselves to be "picked at" and "looked at" more often than they should wish, and cites how for one woman in her research sample, despite having confidence in the medical team her feeling of "losing control" persisted. In discussing his own experience of testicular cancer Frank (2001) describes having to submit himself to medical workers for whom he knew he was another category requiring tasks to be completed, "In treatment, I knew I would become a task that workers would have to address as one of a series of tasks that were part of a working day" (p.361). Likewise, van der Riet (1998), in her qualitative research with 18 cancer patients, documents how one woman spoke of her breasts as private yet when

she became ill with breast cancer, her breasts became the public property of medical discourse.

Nonetheless, it has been suggested that the acquisition of new coping strategies such as information seeking in conjunction with regaining an internal locus of control (taking greater control over decision-making) may lead to the integration of cancer into everyday life (Ramfelt, Severinsson & Lutzen, 2002).

### **3.6 Chapter summary**

Accordingly, a breast cancer diagnosis can elicit a variety of emotional responses and as such places extraordinary demands on women's coping abilities (e.g. Landmark, Bohler, Loberg & Wahl, 2008). Indeed, women's acceptance of their diagnosis, post-surgical body and altered self and whether they will regain an emotional balance, manage uncertainty and improve quality of life, depends on their stress assessment, coping mechanisms and sense of locus of control.

### **3.7 The present study**

While the number of published longitudinal studies investigating the experiences of individuals with cancer has increased over the course of the last five years a paucity of qualitative research on breast cancer remains. However, as demonstrated throughout the preceding chapters women constitute the vast majority of breast cancer cases and the disease holds specific connotations for women given the cultural meanings ascribed to women's breasts. The literature reviewed highlights the importance of breasts to women's sense of self and identity and the potential physical and psychological impact of undergoing

breast surgery. Yet, the focus of existing qualitative studies on specific aspects of meaning and experience (e.g. coping strategies, relationships, the healthcare system) limits the extent to which the issues of importance to women at different time points are discovered as well as the interplay of these factors and associated change over time. Furthermore, the lack of UK based research, use of retrospective designs and the overwhelming use of participation criteria including only women undergoing a particular treatment regime (e.g. mastectomy) restricts the applicability of current findings to British women with breast cancer.

As detailed previously the North East of England constitutes a unique study population with a high prevalence of breast cancer and projections suggesting an increase in cases throughout the next decade. It is a region with notable deprivation and which despite a general move in developed countries towards breast conserving surgery reports the highest rates of mastectomy without reconstruction in the UK. Accordingly, the current study aimed to explore women's lived experience of breast cancer over time using a study sample drawn from the North East of England. Specifically, the research sought to capture women's stories of living with breast cancer encompassing aspects of meaning within their experiences from shortly after surgery to one year post diagnosis. This timeframe, also adopted by McCann et al. (2010) and Tighe et al. (2011), recognises the re-classification of cancer from acute to chronic (Tritter & Calnan, 2002). Moreover, in the present study this enabled exploration of women's experiences throughout the healthcare trajectory as they occurred. Consequently, the data presented in this thesis is restricted to this time period. The study design is discussed further in the following chapter which reviews the methodology and research methods utilised.

## CHAPTER 4: METHODOLOGY

### 4.1 Introduction

This chapter outlines the study methodology and research methods used throughout the research process. The novel use of hermeneutic phenomenology supported by illness/treatment grids to explore women's longitudinal experiences of breast cancer is discussed.

### 4.2 Design

Developed by Edmund Husserl as an alternative to the positivist paradigm and a belief that natural science provided an incomplete understanding of human experience the aim of transcendental phenomenology "is to describe human experience as it is lived" (Merleau-Ponty, as cited in Beck, 1994, p. 500). In introducing the study of the 'lived experience' Husserl aimed for methodological objectivity and being influenced by Cartesian duality believed that the mind is directed towards objects, a concept known as 'intentionality'. Paramount to the Husserlian approach is the use of phenomenological epoche, or 'bracketing' whereby the researcher seeks to put aside any pre-conceived ideas pertaining to the phenomenon under study. Husserl additionally advocated the putting aside of any *temporal-spatial* awareness such that only consciousness remained (Barry, 1983) and thus experiences are viewed regardless of context. Husserlian transcendental phenomenology is by nature descriptive and focuses on the structure of experience. The desire to move from such description to interpretation as well as conflicting views with a number of Husserlian concepts resulted in Martin Heidegger, a former student of Husserl, to develop hermeneutic phenomenology.

The philosophy of hermeneutic phenomenology is both descriptive and interpretive describing individual's accounts of their experience as well as interpreting the meaning they ascribe to these experiences (van Manen, 1990). Heidegger considered hermeneutics to be a '...way of studying all human activities' (Dreyfus, 1991), the basis for interpretation with the aim of allowing the text to speak for itself (McConnell-Henry, Chapman and Francis, 2009). The rejection of mind-body duality resulted in a focus on deriving 'meaning from being' (Mulhall, 1993, 2005) and the coining of the term *Dasein*, a concept that Heidegger argued was not static and thus cannot be objectively measured (Stumpf, 1994; Stumpf & Frieser, 2008). Suggesting that understanding is at the core of human existence the notion of bracketing was also refuted with Heidegger postulating that the researcher is a legitimate part of the research, given their *Being-in-the-world* of the participant. He argued that the researchers' prior knowledge and understanding influenced their ability to interpret the data, the notion of fore-structure or fore-conception (Dowling, 2004), and that no interpretive research can be free of the judgement or an effect of the researcher. Furthermore, having such prior knowledge was seen to ensure that the questions asked would be pertinent to the inquiry (Thompson, 1990 as cited in McConnell-Henry, Chapman & Francis, 2009). A process of questioning and re-examining the text was seen as generating a cycle of ideas regarding what it might mean to be, the so called hermeneutic circle. Understanding is accordingly achieved via interpretation and the hermeneutic circle which suggests that everything is interrelated and experiences can be considered as a whole or in parts (e.g. Heidegger, 1996). Consequently in considering parts of an experience (the data) as well as the whole experience (understanding of the



phenomenon) the circular process whereby each element gives meaning to the other is initiated.

In contrast to Husserl, Heidegger emphasised the importance of context, believing that it influences both existence and experience as humans are at all times immersed in their world (Steiner, 1978). Moreover, he contended that as past experiences impact upon present and future to conceptualise human experience in an a-temporal manner, as postulated by Husserl, was not possible (McConnell-Henry et al., 2009). Gadamer (1960/1995) added to Heidegger's hermeneutic phenomenology suggesting that it is via conversation, through the language of an interview, that a phenomenon, something that was previously concealed, is revealed. In other words, through interpretation meanings in transcripts that participants themselves may not be able to articulate may be explicated. In acknowledging that meaning is unique and is within the particular historical and cultural contexts relevant to the individual, more interpretative engagement with the data is advocated, consequently going beyond the level of analysis associated with Husserlian transcendental phenomenology (Rapport, 2005). More recently Max van Manen (1990) has furthered the work of Heidegger expanding on the hermeneutic nature of his philosophy in emphasising interpretation via reflection on language.

While phenomenologists might have similar objectives the philosophical and epistemological standpoints of Husserlian transcendental and Heideggerian hermeneutic phenomenology differ. It is proposed that the choice of methodology should be governed by the research question and the philosophical implications inherent in the question as well as the epistemological perspective of the researcher (Caelli, 2001). Specifically, the

current research was underpinned by the approach of van Manen (1990), though is grounded in that of Heidegger and Gadamer, in order to illuminate understanding of women's experiences of breast cancer throughout the healthcare trajectory by revealing the meanings embedded in text of the interview transcripts (van Manen, 1997).

As the focus of this research was on women's experiences of breast cancer throughout the healthcare trajectory a longitudinal approach was taken. While longitudinal qualitative methods have been used extensively in sociological and social history research to explore life course patterns they have been slow to permeate breast cancer and health psychology research. As outlined in the previous chapters women's experiences and responses to breast cancer may differ given a variety of factors. Furthermore, if experiences are viewed as the product of time and place and accordingly multiple realities exist then experiences must change over time. A longitudinal qualitative approach aims to capture the fluidity of these experiences and provide rich information pertaining to such change. Accordingly, longitudinal qualitative research would seem to be ideally suited to exploring women's experiences of breast cancer in the year post diagnosis and in doing so offer information relevant to policy and practice. Though crucially, the present study aimed to explore women's experiences of breast cancer as they occurred rather than collect long-term retrospective accounts. Semi-structured interviews were conducted to enable a conversational style of interviewing necessary for hermeneutic phenomenology allowing meaning to emerge between the interviewer and interviewee while ensuring focus on the phenomenon. The use of semi-structured interviews as opposed to structured interviews enables participants to tell their stories and

respond to questions and probes without the requirement of a specific answer thus providing greater breadth and richness of data (Morse & Field, 1995).

Unlike other interpretative phenomenological methods (e.g. Interpretive Phenomenological Analysis) hermeneutic phenomenology proposes greater flexibility during data collection with the goal of encouraging the production of meaning between interviewer and interviewee. A unique aspect of the present study is that this interview process was facilitated via the use of an adapted life grid approach in order to enhance the implicit meanings to be elicited through interpretation of text. The history of life grids began in health inequalities research with the exploration of life course information (e.g. Holland, Berney, Blane, & Smith, 1999) as well as in sociological research studying social change and economic life (e.g. Gallie; as cited in Parry, Thomson, & Foukes, 1999). Such a method is typically used to provide a summary of major life events in a time line fashion. In previous research (e.g. Parry et al., 1999) the first column consists of dates (or years) usually followed by columns depicting, for instance, the categories of personal, occupational, residential, health, or family. The data is collected during an interview and is by nature retrospective as the participant is asked to provide information on past events. The approach has been adopted in these fields as it allows the interviewer to see with ease the clustering of life events and their impact on, for example, health (e.g. Holland et al., 1999). The predominant criticism of this approach is that of the accuracy of information recalled. However, in hermeneutic phenomenology a reflection of historical events has meaning in its own right - unravelling its meaning is more imperative than a correct account since it might reveal concealed experiences interwoven in contradictions and factual inaccuracies which might be crucial in understanding women's lives. Consequently, for the

purposes of the present research the life grid was developed not as a means to collect retrospective data but as a qualitative research tool to aid the interview process.

Parry and colleagues (1999) found that completing the grid (while in the context of smoking history) was a joint endeavour which necessitated the co-operation of the respondent, resulting in a "productive rapport" (p.9). The authors note that this rapport can be vital because the quality of data in the interview transcripts is largely dependent upon the discussion around events entered into the grid and associations made between them. Such a notion would seem to complement that of hermeneutic phenomenology and facilitate the process of eliciting the landscapes of the selves. Furthermore, as the respondents used events as markers it was easier for the researcher to return to these in more depth in subsequent interviews. Parry and colleagues additionally state that the grid method appeared to enable respondents to draw on personally traumatic experiences in a way which diffused what were potentially emotionally charged areas. This was felt to be highly pertinent given the nature of the present study. Finally, grid interviewing has been found to allow respondents to take some control over the course of the interview and in the construction of their biographies (Parry et al., 1999) and can in turn increase their enjoyment in the interview process (Holland et al., 1999).

In the present study illness/treatment grids were completed during the course of each interview by the researcher in conjunction with the participant, and documented in summary format the key experiences and perceptions discussed during the interview. The grid columns were designed to aid the documentation of key events in each woman's experience (e.g. treatment commencement,

completion) as well as decision-making processes, women's perceptions of the self and additional comments. An example of a completed illness/treatment grid can be found in Appendix 1. This depicts 'Laura's' reported experiences at each data collection point in the year following diagnosis, charting her diagnosis, course of treatment and her perspectives on the decision-making process, perceptions of control and impact on her sense of self and identity. The final column of the grid was used to note, for example, psychological responses and coping mechanisms. 'Laura's' grid provides a snapshot of her experiences and includes direct quotations from each interview that captured the researcher and issues that 'Laura' perceived to be of particular importance at that given time. This joint venture between researcher and participant was led by the woman's experiences, facilitating a sense of control over the interview situation. While the illness/treatment grids were not analysed per se, as they were utilised as a tool to aid the interview process, the content of the grids is inevitably reflected in the emergent themes.

The study aimed to conduct three interviews including completion of the illness/treatment grids throughout the 12 month period following the diagnosis of breast cancer. This was in order to capture women's experiences from shortly after diagnosis to early follow-up, while minimising issues associated with retrospective data collection. The ongoing completion of the grids served to provide an *aide memoire* for researcher and participant with regards to the previous discussions and facilitated further reflection on issues highlighted throughout each woman's experience. Three interviews were conducted with sixteen of the twenty participants with the remaining four participants each completing two interviews. One woman had become a full-time carer for a terminally ill relative between interviews one and two while during this time

another woman lost her mother for whom she had been a carer and, given such circumstances, the researcher did not deem it appropriate to request an additional interview. One woman was non-contactable during the third phase of interviewing and another was experiencing ill health unrelated to breast cancer.

Interviews lasted between 35 and 90 minutes and were conducted in participants' homes, at their request. In order to adhere to ethical guidelines participants were not seen for the first interview until after they had undergone surgical intervention. The time between diagnosis and surgery was typically one to two weeks. The range of time between diagnosis and the first interview was one to five months with an average of 2 months since diagnosis and one month post-surgery. The time elapsed between diagnosis and the second interviews ranged from four to ten months with a mean of 6.5 months. Third interviews were conducted ten to seventeen months after diagnosis, with an average of 13 months post diagnosis. The timing of women's interviews was based upon the circumstances of the participant and the researcher during each period of data collection.

#### **4.3 Participants**

The sample was recruited from a symptomatic breast cancer unit in the North East of England. In line with hermeneutic phenomenology purposive sampling was undertaken such that all participants shared the experience under exploration, in this case women with a diagnosis of breast cancer. Women attending the unit between April and December in 2006 receiving this diagnosis, who were aged 18-75 years and were able to give informed consent, were approached to participate by the breast care nurses. Given the busy nature of the clinic, time constraints during periods of staff absence and a requirement set

by the hospital ethical approval board to implement a delay between diagnosis and first researcher contact in order to ensure informed consent, recruitment was guided by the breast care nurses. For such reasons it was not possible to monitor exact response rates however in order to contextualise the sample size of this research, the clinic where recruitment was undertaken receives over 3000 new referrals each year, of which approximately 200 women are diagnosed with breast cancer annually. However, diagnoses of new cases of breast cancer can vary widely week to week (averaging 2-5 cases) and are often noted by clinic staff to occur in clusters. Indeed, during the first half of the recruitment period the number of women diagnosed was deemed to be lower than average by the breast care nurses. The quantity of data provided by the women recruited in these first few months as well as the recruitment difficulties detailed prompted the researcher to cease recruitment once twenty women meeting the inclusion criteria had returned a signed consent form.

The aim of obtaining a homogeneous sample within this scope was limited by the diversity (detailed below) of women attending the clinic at the time of recruitment. However, all participants underwent surgical intervention, described their ethnic origin as white British and were between the ages of 41 to 68 years (mean age of 54 years). Such characteristics are nevertheless highly representative of the women diagnosed with breast cancer via the clinic each year. For one woman this experience was of a cancer recurrence and for another the breast cancer diagnosis was given ten years after a high risk genetic assessment and bilateral prophylactic mastectomy. At the time of the first interview all women had undergone surgery (either lumpectomy (N=7), mastectomy (N=12) or removal of remaining breast tissue (N=1)) and were receiving additional treatment(s) such as chemotherapy, radiotherapy,

pharmacotherapy or combinations of these interventions. Three women initially underwent a lumpectomy returning for a mastectomy within a four week time period following histology results. One woman completed reconstructive surgery during the timeframe of the study (nine months post diagnosis) and an additional three women were in the process of pursuing this surgery at the time of interview three.

Twelve participants were married at the time of the first interview with one of these women becoming separated from her husband by interview three. Four women were recently divorced with one currently having a partner and the remaining four women were widowed. Nineteen participants had children, of which eight participants had children residing with them. Fifteen women were in full-time employment prior to diagnosis, four women were retired and one described herself as a 'housewife'. A tabulated overview of participant characteristics can be found in Appendix 2.

#### **4.4 Materials**

A study information sheet (Appendix 3), consent form (Appendix 4), debrief sheet (Appendix 5) and a stamped addressed envelope comprised the study materials. A semi-structured interview schedule (Appendix 6) was also constructed to facilitate women to tell their stories. All initial interviews began with the broad lead-in question "Please can you tell me about how you came to be at the breast clinic?" These first interviews focused on the events that had taken place from identification of possible breast disease and for some women their history of breast disease to the point in the healthcare trajectory that had been reached to date. Participants were encouraged to freely describe their experience though discussion was supported by prompts where necessary



regarding the process of diagnosis and experiences around undergoing surgical intervention including the impact of these events on their everyday lives. All subsequent interviews began with a review of previous interview discussions which enabled the accuracy of the data and the interpretation undertaken to be confirmed. Interviews two and three were structured around individual participants' experiences over the preceding few months each beginning with the question "Please can you tell me about your experience of breast cancer since our last interview?" Again participants were encouraged to express their experiences without constraint with questions including "How would you describe yourself at this moment in time?" Questions focused on the emerging themes relevant to the individual. The illness/treatment grid (Appendix 1) was completed by the researcher during the course of each interview being led by participants' individual experiences and perceptions. This documentation of experiences was listed under the headings of events, decision-making, control, self and other comments. Participants were given a copy of their grid to review at the beginning of interviews two and three providing a visual representation of their reflections and their progress. This methodological tool and the related outcomes with regards to three case studies were presented at the European Health Psychology Conference in 2007 (Swainston, Campbell & van Wersch, 2007; Appendix 7).

#### **4.5 Procedure**

Ethical approval was obtained from the School of Social Sciences and Law University of Teesside research ethics committee as well as from the University Hospital Research Approval Board and the Regional Committee of the National Research Ethics Service (see Appendix 8). An honorary contract was awarded

by NHS Trust for the duration of the study. Once approval had been obtained study information sheets and consent forms with stamped addressed envelopes were supplied to the symptomatic breast cancer unit. The breast care nurses disseminated these materials to women newly diagnosed with breast cancer who they felt would be able to give informed consent. Upon receipt of signed consent forms participants were contacted to arrange a suitable time for interview. Written consent was obtained prior to commencement of each interview. All interviews were tape-recorded and transcribed verbatim and each illness/treatment grid was typed up ready for the subsequent interview. Participants were given a debrief sheet including details of local breast cancer support groups and a variety of support services available to women with breast cancer. Each woman was assigned a pseudonym in order to protect their identity and maximise anonymity. Only the researcher had access to the data provided by participants and all information stored electronically was password protected and written documentation was stored securely at the University of Teesside.

#### **4.6 Data analysis**

Data were analysed in accordance with van Manen's (1990) approach utilising his six steps for hermeneutic phenomenological research as a framework for the analysis:

1. Exploring a phenomenon of interest to us and commits us to the world
2. Investigate experience as it is lived rather than as we conceptualise it
3. Reflecting on the themes characterising the phenomenon
4. Describing the phenomenon through the writing and rewriting

5. Maintaining a strong and oriented (psychological) relation to the phenomenon

6. Balancing the research context by considering parts and whole

This method of analysis moved away from an application of coding in order to elicit meaning hermeneutically (Langdridge, 2007). The aim was to engage in a 'free act of "seeing"' (van Manen, 1990; p.79) and search for what is *universal*, the general meaning, from the *particular*, in relation to a specific person or situation.

The data analysis process was applied to the research data as follows however interpretation began during the first interview and developed throughout the course of data collection:

1. Analysis of all first interviews (20)
2. Analysis of all second interviews (20)
3. Analysis of all third interviews (16)
4. Overall analysis of interviews (56)

In depth reading and re-reading of each relevant transcript ensured emersion in the data following which data analysis began with the holistic or sententious approach. During this stage individual transcripts were read and sentences or phrases that were deemed to be representative of women's experiences of breast cancer as a whole were identified. This provided understanding of women's stories of breast cancer. Subsequently, the selective reading or highlighting approach involved reading the text several times and highlighting statement(s) or phrase(s) in order to reveal elements of these experiences. The

quotations that best captured women's experiences and demonstrated similarities and differences across individual women's experiences as well as across the three time points were highlighted. While a line by line analysis approach can also be adopted given the quantity of data generated by this research this was not felt to be the most appropriate method.

The sententious and highlighting approaches were combined in order to ensure a balance was obtained between the whole and parts and that emergent themes were representative of the phenomenon. A summary was written containing an interconnected list of themes and sub-themes for each interview/participant and comparisons were made across each woman's story over time. Writing and re-writing was undertaken throughout the analysis process in order to aid the development of descriptions of participants' experiences. This is viewed as an essential part of phenomenological reflection (van Manen, 1997) and in conjunction with the completion of a research journal tracking the research process and the researcher's thoughts and feelings, added greater depth to the interpretation.

At the core of hermeneutic phenomenology is the notion that the researcher is part of the research as they become 'in the world' of the participant and accordingly the approach recognises the ongoing influence of the researcher via the research practices conducted. The researcher's own history is seen as influential in framing understandings and interpretation is not deemed to be an additional procedure but rather comes from the researcher when being involved in the world that they are investigating. Indeed, when researching phenomenological approaches the acknowledgment that no interpretative research can be free of judgement or the effect of the researcher was a concept

that matched my own philosophy. Reflexivity is further addressed in the discussion chapter (page 345) where epistemological reflexivity, relating to the assumptions underlying the research and how these have shaped the research process, as well as personal reflexivity, relating to aspects specific to the researcher (Willig, 2001) are reviewed.

Cross-checking interpretations with individual participants, with the assistance of the life grid to enable a review of previous interview data, ensured interpretations were grounded in the data. The ultimate objective was to use the voices of participants to illuminate data analysis such that 'evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience' (Sandelowski, 1993, p.1) was revealed. Engaging in free imaginative variation the phenomenon (e.g. van Manen, 1990) i.e. women's experiences of breast cancer was imagined without each theme. If the phenomenon was deemed to lose its meaning, the theme was considered an essential element. For this study women's real names were replaced with a pseudonym for reason of confidentiality.

The themes that emerged from data analysis are considered in the following three chapters which represent the medicalisation of breast cancer, women's perceptions and management of the body, and women's psychological responses and adjustment to breast cancer. Within each data chapter a series of themes are presented some of which are subdivided into several sub-themes. Indeed, the longitudinal nature of the current study elicited a multitude of findings some of which emerged at one time point while others permeated women's experiences throughout the year post diagnosis. In accordance with the diverse nature of the themes identified, the research findings have been

compared to the extant literature in the data chapters. The discussion chapter subsequently considers the participants 'whole' experience of breast cancer by linking themes in the context of policy developments and theoretical perspectives. Specifically, the discussion aims to consider the participants' experiences of breast cancer in order to develop current theories of self, identity, embodiment and coping (as discussed in Chapters 2 and 3).

## **CHAPTER 5: THE MEDICALISATION OF BREAST CANCER**

### **5.1 Introduction**

This chapter depicts the elements of the twenty women's experiences that reflect the medicalisation of breast cancer. The journey through the healthcare trajectory is discussed from the point of symptom identification and waiting prior to help-seeking to the process of diagnosis and treatment decision-making. The way in which these women's lives become medicalised through treatment regimes and hospital appointments and the resulting impact on their identity and self is discussed. Acceptance of medical opinions and trust in healthcare professionals to assist in removing breast cancer from the body and participants lives is addressed with a focus on the consequences for treatment decision-making. Subsequently, the influence of cancer schema are reviewed including participants perceptions of breast cancer and coping strategies pertaining to information provision and acquisition. Finally, control and responsibility are discussed with regards to breast health (primarily breast self-examination) incorporating the struggles experienced resuming responsibility for healthcare following hospital-based treatment completion. The timing of the emergence of each theme/sub-theme is considered within the context of the year post diagnosis. The findings detailed in this chapter that are specific to treatment decision-making have recently been published (Swainston, Campbell, van Wersch & Durning, 2012) and can be viewed in Appendix 9 though all themes are considered here in greater depth. The chapter commences with participants experiences of waiting throughout the year following diagnosis.

## **5.2 Waiting**

As noted by Mulcahy, Parry and Glover (2010) waiting is integral to the experience of a cancer patient "waiting for tests, waiting for lab tests, waiting for results, waiting for diagnosis, waiting for prognosis, waiting for remission, and waiting for recurrence" (p. 1062). The present study has uncovered that in the context of breast cancer waiting began prior to diagnosis, was central during the trajectory of healthcare and permeated participants' lives to early follow-up. The first interviews conducted shortly after surgery in which the women focused on describing the identification, diagnostic and treatment decision-making processes were particularly crucial in uncovering the elements encompassing this theme. The multifaceted nature of the participants experiences of waiting is represented through several sub-themes, the first of which, discussed below, considers waiting with regards to help-seeking behaviour.

### **5.2.1 Waiting to seek help**

Participants were recruited from a symptomatic breast unit and accordingly these women were being seen routinely at clinic due to prior breast disease, had been referred following a routine mammogram or after presenting to the GP with either a lump or a change in breast tissue. While some women in this latter group sought GP advice immediately, numerous women waited to do so. The possible implications of such delays have been demonstrated via a systematic review of 87 studies which found that longer delays in presenting with a breast symptom is associated with lower survival rates from breast cancer (Richards, Westcombe, Love, Littlejohns & Ramirez, 1999).



Delays in help-seeking following self-identification of a breast symptom have been previously reported via a quantitative survey of one hundred Irish women (O'Mahony & Hegarty, 2009). The paper stated that 26 women delayed seeking help from a healthcare professional such as a GP of whom 14 women delayed from one to three months and 12 women did not seek help for over three months. The study additionally recorded that women who had greater anxiety about the breast symptom delayed less as did women who believed that early detection was crucial. Conversely, belief that the breast symptom was harmless and temporary was associated with a delay in help-seeking. Social issues including lack of a confidante and a complex lifestyle were also positively related to delay. The present study supports the latter of these findings as participants focused on others to the detriment of their own health.

*'I went via my GP because I found a lump in my left breast. The trouble was I had to delay that because my mother was ill...so it was about seven weeks after I found the lump that I went to clinic. I know it's stupid of me. I'm a trained nurse and I know it's a stupid thing to do but I just didn't have the opportunity'* (Lily; Interview 1; Lines 5-6; 16-19).

Torpy, Burke and Glass (2006) noted that women neglect their health needs focusing instead on their spouse and children yet this research has identified that caring for older relatives was more commonly the reason cited by women for the delay. The majority of women participating in the current study were midlife, a stage 'where a number of competing status passages are experienced' (p.420) including care for elderly relatives, changes in employment, marital status and health concerns (Ballard, Kuh & Wadsworth, 2001). These issues commonly featured in women's lives prior to and during their experience of breast cancer and may be pertinent in this sub-theme. One

of the youngest participants reflected on how her caring responsibilities for her child instigated help-seeking for her own breast symptom.

*'I just found a lump. I was in the house...I must say I waited a few weeks, which is a bit naughty isn't it and the reason I went, funnily enough, is because I had to take my son to the doctors and I thought right while he's in, I'll ask them to look at this. I went to the doctors on one day... and I was referred within a week'* (Laura; Interview 1; Lines 5-9).

The two aforementioned quotations depict that participants who did delay seeking medical advice assigned negative connotations to doing so by highlighting their awareness that delaying help-seeking could be detrimental to their health. Uncertainty as to the nature of the lump particularly when previous breast disease had been experienced was influential in this waiting process.

*'Well I'd actually had the lump for quite some time and it was only by chance that I mentioned it to the doctor...I mean twenty years ago I actually went to the General (District General Hospital) because I had a lump in exactly the same place and nothing came of that, they just said it was a little bit of a fatty deposit. So, all those years when I checked myself I just thought I had lumpy boobs'* (Amanda; Interview 1; Lines 9-10, 20-23).

The misattribution of symptoms to non-cancerous conditions, including past chronic conditions, as well as patient monitoring of symptoms have been found to be associated with patient delays in seeking help in a UK based sample though to a lesser extent with breast cancer patients compared to other cancers (Molassiotis, Wilson, Brunton & Chandler, 2010). Nevertheless, the present

research suggests that some participants did monitor their breast symptom as a result of the uncertainty experienced.

*'Basically I examined myself and thought I felt something but it wasn't a definite. You see six years ago I had a lump in this breast but it was a definite. You know it was yeah, could see it, it was there, no problem...For a couple of weeks about a fortnight or three weeks I didn't.. .because one minute it seemed to be there and the next minute it didn't' (Maria; Interview 1; Lines 5-7, 10-12).*

These elements are present in the following extract from Jenny's initial interview though in addition she was the only participant to explicitly describe attempting breast self-examination when identifying a potential symptom.

*'It wasn't a lump, it was a firmness and I'd been watching a programme, This Morning, and there was a lady on there and they were showing how to examine yourself. I was going in the shower so thought I'm gonna have a go at that so I did and I could feel the firmness but I thought well I breastfed the kids so maybe one side has got firmer than the other. I left it a week and then did it again and no, it was still there so I thought I'd better go and see (the doctor)' (Jenny; Interview 1; Lines 9-14).*

The misattribution of breast abnormalities to breastfeeding experiences has been reported elsewhere (Lu, Lin & Lee, 2010) as resulting in a delay to seek help. In the current study pain was one of the factors cited as inducing the participants to overcome their uncertainty and visit their GP.

*'It was only that I'd turned over in bed and it had started to nip and I actually mentioned it (to the GP)' (Amanda; Interview 1; Lines 23-25).*

As discussed further in the final theme in this chapter participants frequently cited a belief, otherwise termed cancer schema, that cancer was associated with pain. The emergence of this symptom may have led these women to reassess the potential severity of the change in breast tissue and instigate behaviour change, in this case seeking medical advice. Accordingly, the lack of pain often led participants to believe that they could not have breast cancer and this lack of symptomatology was linked to greater difficulty accepting their diagnosis.

*To be honest I didn't believe it when I was told because you don't feel any pain with it. I didn't feel it at all* (Elizabeth; Interview 1; Lines 89-90).

The absence of physical discomfort has been identified as leading women including those with a visibly noticeable breast abnormality to delay seeking medical help (Lu et al., 2010). While this aforementioned research is limited in its applicability due to cultural differences which led some participants to seek alternative therapies prior to a medical opinion and women feared accepting medical treatment, all of which was not identified in the present study, delay due to a lack of pain is supported.

Contrary to the findings of O'Mahony and Hegarty (2009) and Illingworth and colleagues (2010) having someone to talk to about their breast symptom did not always encourage help-seeking behaviour. The following quotation from Fiona's first interview suggests that this actually led to greater uncertainty and an extended wait to attend the GP.

*I kept saying to him (husband) I've got lumps and he was saying it's just your boobs, just your boobs. I kept saying to him can you feel it and he kept saying no* (Fiona; Interview 1; Lines 36-38).

One large scale mixed methods UK based study found that men consistently ignored health symptoms and avoided seeking help from healthcare professionals (Sharpe & Arnold, 1998 as cited in Galdas, Cheater & Marshall, 2005). Similar results have since been reported (e.g. Sanden, Larsson & Eriksson, 2000) via qualitative research as have men's attempts to normalise symptoms (Gascoigne & Whitear, 1999). These factors may have been influential in Fiona's husband's reaction to her symptoms. Locally advanced breast cancer presentation following a delay in help-seeking has been found to be associated with passivity, denial and fatalism in both women and their male partners as identified through qualitative semi-structured interviews (Mohamed, Williams, Tamburrino, Wryobeck & Carter, 2005). The authors report that these views were not endorsed on psychometric measures and that women reported giving socially desirable answers on these tests and consequently urged caution in relying on psychometric data as women's responses may be influenced by the same factors inhibiting their help-seeking behaviour.

Trusting her own experiential knowledge ultimately led Fiona to acquire professional help. Furthermore, the following quotation from Margaret's first interview illustrates that, as reported elsewhere (O'Mahoney & Hegarty, 2009; Facione & Facione, 2006), some women consciously choose to keep their discovery from others until after particular events such as a holiday.

*'I found a lump in my breast. I'd had it for about six or seven weeks because I knew I was going on holiday and I thought I'm not gonna say anything until I've had my holidays and worry everybody. Anyway, we came back off my holidays and I went the next day and I was referred'* (Margaret; Interview 1; Lines 5-9).

This indicates an element of distraction while waiting to seek help perhaps to manage the anxiety and fear of having found a potentially life-threatening breast lump. The suspicion of cancer is argued to be the moment at which an individual enters liminality (Little, Jordens, Paul, Montgomery & Philipson, 1998), a term often used to describe the phase between health and illness (e.g. Forss, Tishelman, Widmark & Sachs, 2004). In the present study, at this stage of having identified an abnormality yet not receiving a diagnosis, women may neither be classified as healthy nor ill.

Delays were not only the result of women themselves waiting to seek help but for several participants delays were experienced in being referred from the GP to the breast clinic.

*'I found a lump erm.round about May this year, went to my GP. The first time she didn't think it was anything, second time she didn't think it was anything but in July before I went on my holiday I just felt there was something not quite right so I went back. She referred me and in August when we came back off our holidays I went to see (the breast surgeon)'*  
(Gillian; Interview 1; Lines 9-13).

Diagnostic delays due to primary care practitioner factors were equally noted by Molassiotis and colleagues (2010). Accordingly, there are implications for early cancer detection and fast referral for diagnostic investigations advocated in the NHS Cancer Plan (Department of Health, 2000). Given these results it is perhaps not surprising that while some targets have been met (e.g. implementing an age extension for breast cancer screening), 'slippages' have occurred in meeting others (e.g. raising public awareness of the signs and symptoms of cancer) (Department of Health, 2006). Once help-seeking had been instigated and referral to the symptomatic breast unit initiated, all women

interviewed described being seen in accordance with the two week rule (discussed in Chapter 1, p.23). However, the participants' experiences of waiting did not cease and the following sub-theme considers the wait for a diagnosis of breast cancer.

### **5.2.2 Waiting for diagnosis**

Similar to the findings of Mulcahy, Parry and Glover (2010) who explored waiting in the context of a variety of cancer patients, the waiting process for women in the current study receiving a breast cancer diagnosis was traumatic. During the first interviews all participants described the process leading up to diagnosis. As outlined in Chapter 1, this began with a physical examination and subsequently a mammogram and either fine needle aspiration or a core biopsy, the latter of which the relevant women described as the most physically painful aspect of their experience. While for the majority of participants investigations and diagnosis happened on the same day the notion of waiting was integrated within their descriptions.

*'I was there ages. I mean I thought I'd get to work but I had to have the night off from work. My appointment was something like ten thirty and I was still there at five o'clock. I waited about a bit, she checked me and then I seen her face fall and "right, go and have a mammogram"...So I had to wait around for the mammogram, goes back after the mammogram and "there's a shadow...I'm afraid it is, can we do a biopsy?"...Then I had to wait for the results' (Jenny; Interview 1; Lines 35-39; 41-44; 52-53).*

The above quotation is one of several suggestive of the breast surgeons preparing women for receiving bad news, a behaviour which led to a wait for

their worst case scenario. For Susan waiting to hear the word cancer was one of the most difficult aspects of her experience.

*'I think waiting to hear her say the words was worse than hearing it'*  
(Interview 1; Line 90).

As illustrated below the participants who were experiencing a recurrence or who had a family history of breast cancer described waiting, in some cases years, to be given this diagnosis.

*'My daughter had breast cancer four years ago and so I've been...sort of...waiting because I know it's hereditary. I think I'd half been expecting it'* (Pauline; Interview 1; Lines 7-9).

Mental preparation has been reported elsewhere through analysis of written narratives of receiving a cancer diagnosis (Salander, 2002) though this was specific to the diagnostic phase, an element which was also present in the accounts of several participants.

*'Somehow, something in me just knew. I was saying yeah, it could only be something like that again (cysts) but we don't know but just in case it is we have to be prepared. I said well whatever it is I'm looking on it as if it is because then if it isn't great and if it is then I'm ready for it'* (Maria; Interview 1; Lines 62-66).

Accordingly, as illustrated above Maria, who suspected a breast cancer diagnosis was likely, began a process of mentally preparing herself and her family in order to ensure readiness for the experience ahead. The time between diagnosis and primary intervention constituted an additional period of waiting and is described in the next sub-theme.



### 5.2.3 Waiting for intervention

Contrary to previous findings the most distressing period of waiting was found not to be that leading up to receiving the diagnosis of breast cancer but from the time of diagnosis to undergoing surgical intervention despite all participants undergoing surgery within one week following diagnosis.

*'If I could have gone into hospital and had my breast taken away the next day I would quite happily have done that'* (Rose; Interview 1; Lines 112-113).

Joan elaborated on this element of waiting as well as highlighting the desire for reassurance from healthcare professionals and medical regimes.

*'I think initially its devastating news that you get then once you've had the bad news and had it delivered you're looking for somebody to tell you something positive. You're looking for that reassurance that there is treatment available, that you're not going to die, that you know.this is your plan of action and I think you just wanna get started. You don't want any delays, you just want it to happen yesterday'* (Joan; Interview 2; Lines 267-273).

Pauline further reflected on why this waiting period was so distressing:

*'It's the living with it and nobody doing anything'* (Pauline; Interview 1; Lines 36-37).

Waiting is theorised to be associated with a loss of control for those made to wait (e.g. Levine, 1987) and in relation to healthcare can elicit feelings of panic, anxiety, depression, and uncertainty (Bailey, Wallace & Mishel, 2007). In support of the findings of the present study this period, termed preliminary

diagnosis as the extent and aggressiveness of the tumour is unknown, has been found to elicit the highest levels and percentages of distress among 102 women with breast cancer (Andreu et al., 2012). Knowing that they were currently living with cancerous breast tissue not only had a psychological impact but influenced everyday activities of daily living.

*'When I first found out what it was and I was waiting to go into hospital whenever I went in the shower I couldn't take my bra off. I couldn't wash myself, couldn't touch that area knowing that it could be killing me'* (Jenny; Interview 1; Lines 213-216).

Lindwall and Bergbom (2009) reported similar findings in women perceiving their bodies to have failed them by housing a life threatening tumour. This led to a loss of confidence in the body and fear of an uncertain future, again linked to the unpredictability of breast cancer and lack of symptoms experienced.

*'It's hard to describe because. . . .because it's been there and it seems to come from nowhere and you have no signs and if I hadn't prodded myself that day...I might have needed chemo. You just have that fear now all the time'* (Jenny; Interview 1; Lines 190-193).

As such, issues regarding waiting extended to receiving results from surgery including those pertaining to lymph node sampling.

*'Once I came round from the anaesthetic I had a strong feeling of relief but had the big fear of has it spread? That was a couple of weeks later when you find out so you're sort of in limbo for those couple of weeks and that is a horrendous time but you've got to try to be positive'* (Jenny' Interview 1; Lines 146-149).

For participants requiring additional treatments the concept of waiting continued throughout their descriptions of their experience both in terms of commencing and completing individual interventions.

*'I went to see the oncologist about three weeks ago and he said the waiting list was about ten weeks, which I mean really, you want to go in and get it over and done with. It's like I'm hanging on and hanging on...I feel it's inconvenient because I'm having to wait. I really want to get back on with my life and I feel as though I can't do that until I've had the radiotherapy'* (Margaret; Interview 1; Lines 100-103; 128-130).

Similarly, for the few participants in this sample who sought reconstructive surgery a further phase of waiting was experienced.

*'I was quite disappointed at the time because I had to wait five months for my appointment with the plastic surgeon, which I thought was a long time really. Erm...but you know waiting lists are waiting lists aren't they'* (Gillian; Interview 2; Lines 6-8).

Gillian further commented:

*'I just want my life back and I will but not until I've had the reconstruction'* (Line 47).

Gillian's quotation reflects the ongoing desire demonstrated by all participants throughout this research to regain their life and to return to how things had been prior to receiving their diagnosis of breast cancer. This is reflected in the subsequent sub-theme, waiting for normality.

#### **5.2.4 Waiting for normality during a medicalised existence**

The notion of waiting was found to be integral to participants' discussions around striving to regain 'normality' while experiencing a medicalised existence.

The disruption to the life-world (Bury, 2001) throughout the year following diagnosis was perceived to hinder a return to these women's former identity and self. The aim to return to life and the self as it was prior to diagnosis, in other words a desire for a restored self (Charmaz, 1987) rather than a "new" self, was evident throughout the healthcare trajectory as the study participants lives revolved around medical regimes.

*'I think when you're going through all of this, a mastectomy in the December then chemotherapy January to May, radiotherapy mid June to July, then another mastectomy in August so I haven't been in control in as much as everything I've done I've had to look in my diary to see where else I'm supposed to be' (Susan; Interview 2; Lines 20-24).*

In line with the findings of Kelly and Field (1996), those women experiencing hospital-based treatment regimes found breast cancer to dominate their lives disrupting their participation in the world and compounding deviation from normality.

*'I didn't feel in control of the radiotherapy because for that whole time, for that whole twenty days your life's not your own, it's literally around your hospital appointments. You've got to plan your day, everything around that hospital appointment so you can never possibly have control over it' (Laura; Interview 3; Lines 183-186).*

As illustrated by Moch (1995) being provided with a hospital appointment in itself takes control away from women and as demonstrated in Laura's quotation acquiring a medicalised existence contributed to her sense of lost control. The women interviewed began to describe experiencing an existence that was medicalised being focused around hospital appointments and as the body

became subject to treatment regimes these women seemed trapped in the present and continued to wait for a return to their former lives and self.

*'I think once the chemotherapy's finished I'll get back to normal* (Louise; Interview 2; Line 190).

Accordingly, rather than accepting a degree of contingency as discussed by Frank (1995) such participants pursued control through a disciplined body (Frank, 1991) by focusing on the completion of medical regimes. While undergoing chemotherapy participants spoke of a contrast between undergoing treatment and the ability to resume a normal life at least for a few days in between treatments. Waiting for treatment completion and a state of normality were nonetheless integral to these women's narratives including that of Louise who, like many other participants, was counting down each treatment.

*'Well I've had three chemotherapies now, so there's three more left to go. The first one was alright it's just the sickness afterwards and you feel weak for about four days and you finally recover...and sort of...the week before your next chemotherapy you're fine and back to normal and then you have to go again. So, the whole process starts again'* (Louise; Interview 2; Lines 5-9).

For participants who were prescribed Tamoxifen the drug was viewed as extending their wait for normality by maintaining an illness identity potentially for five years until the end of the treatment course.

*'When I first knew I was taking Tamoxifen I was gutted. I wanted to have either chemo or radiotherapy so that I could do it in a bunch and get rid of it, be done. Five years on Tamoxifen seemed...oh...'* (Ellen; Interview 3; Lines 306-308).

Participants who had been employed prior to their diagnosis frequently associated normality with a return to work and resuming interactions with others.

*'I suppose...being able to go to work and...to me you lead a normal life when you can see people and just being able to travel in the car to see other places because now you're stuck in your house' (Louise; Interview 2; Lines 197-199).*

Louise's quotation illustrates how treatment regimes can lead to an alienation from the outside world (Charmaz, 1983) and in turn threaten women's identity and sense of self. Similarities to Kleinman's (1988) study of the chronically ill can be drawn in terms of the impact on social occasions though in this research this is through both medical regimes and as is demonstrated in the following chapter, an impact on the body. The existing literature considering women's experiences of returning to work following breast cancer is limited with the few existing studies being dominated by quantitative retrospective designs. A recent literature review (Tiedtke, de Rijk, Casterle, de Christiaens, & Donceel, 2010) found that most women decided to return to work to regain some normality in their lives and while this review is limited by the synthesis of primary studies with differing methodological details, this notion is mirrored in Janet's comment.

*'I'm always busy, I have a job...Now, they've put me on the sick and I'm thinking God.I feel a bit lost without going to work. Financial, that's a big thing as well. So it's changed just like that.lifestyle. I like to still do as much as possible but to think one week I was working and was normal and now this has happened and its.not normal. It's not normal, even though you try to keep things as normal as possible' (Janet; Interview 1; Lines 138...141-146).*

Financial pressures have been reported as key factors influencing women's decision to return to work following breast cancer in a UK population (Kennedy, Haslam, Munir & Price, 2007). Experiencing financial difficulties was frequently cited by participants of working age for whom an extensive regime of medical intervention was undertaken. This resulted in these women taking less time to recover before making attempts to regain this aspect of normality.

*'I had about ten or eleven weeks off but I have three jobs but I only got sick pay from one of them so it's a money thing why I've gone back, you know'* (Jenny; Interview 2; Lines 105-106).

Participants' desire to return to normality and their underlying focus on diagnostic processes and treatment regimes substantiates Frank's (1995) restitution narrative in relation to breast cancer. Thomas-MacLean's (2004b) consideration of breast cancer narratives supports its prevalence in women's retrospective accounts of their illness. Participants experiencing breast cancer for the first time consistently discussed their belief that normality would return once they no longer required medical intervention. That said, as previously proposed by Thomas-MacLean (2004b) albeit in relation to women's changed bodies, the discourse of several women eluded to the fact that full restitution (i.e. regaining the life and normality that they had previously) was not possible.

*'I've always gone to full time work and I can't even go back to the job that I was doing so I don't know what I'm going to do. It's driving me absolutely mad. I'm always so busy and I just can't do anything until I've finished all this treatment'* (Emma; Interview 1; Lines 51 -54).

While participants had waited throughout their experience to return to normality, and anticipated a return to activities of daily living and their working lives following treatment completion, this was often not the case.

*'Well when I went back to work I really thought I was ready to go back to work. I thought I'd more or less got over everything and I was back to normal but when I got back to work I realised that I really wasn't ready to come back. I really couldn't get my head around my work, it was taking me three times longer to do things because things just weren't registering. I found I was quite weepy and erm.and I'm not really a weepy person. Once I'd got back to work it took me really up to the Christmas time to feel back to normal and that I was in control of what was going on whereas before I just didn't feel as if I was in control. Then once I started to feel like that it gradually got better and better and just back to normal really' (Margaret; Interview 3; Lines 9-18).*

Women have previously been reported to experience interference in the return to work due to the physical limitations caused by breast cancer treatment including arm pain, fatigue and poor concentration (Tiedtke et al., 2010). A realisation and in turn a sense of disappointment that returning to "normal" would be a gradual process requiring further waiting was inherent in Susan's description of this time in her journey.

*'I think why I feel frustrated now.all the way through my goal was to get back to work and I didn't really think beyond that. In my head I was gonna be completely back to normal by Christmas which realistically was never, ever gonna happen but because it was in my head I wasn't letting anything get in the way of that' (Susan; Interview 3; Lines 32-37).*

Charmaz (2002) argues that when a hospital is viewed as an alien environment, treatment regimes lead to a disconnection of an individual's real life and everyday habits, and a perception of waiting time or time lost from life may be



evident. This is demonstrated in the below extract as Sarah who had experienced breast cancer over ten years ago reflected on once again experiencing a year waiting for normality.

*'It's meant my life's been put on hold again for another year. I think it takes a year. I was diagnosed in December and I won't finish my treatment until the end of August so its eight months and then it'll take you four months to recover from it, so it's a year you're giving up again'*  
(Sarah; Interview 2; Lines 104-108).

This is suggestive of physical normality returning in the longer-term yet as discussed in the final theme of this chapter moving away from a medicalised existence raised concerns regarding resuming control and responsibility for breast health.

The longitudinal approach employed in this research study has helped to reveal that in the context of breast cancer the concept of waiting is multifaceted and manifests differently over time. Periods of waiting emerged throughout the healthcare trajectory and waiting for normality frequently remained one year post diagnosis. It has been argued that waiting is often associated with the constraints of healthcare systems such as high workloads and understaffing, which may lead to more traditional doctor-patient relations with an authoritative doctor and passive patient (Street, 2003). This may in turn limit patient's opportunities to gain control over their illness and participate actively in the treatment decision-making process (Sharf & Vanderford, 2003). Women's experiences of treatment decision-making and specifically their role in this process are explored further in the upcoming theme.

### **5.3 Role in the treatment decision-making process**

The increasingly short timeframe between diagnosis and surgical intervention (in the case of the clinic from which the study participants were recruited this was approximately one week) has resulted in a need for rapid surgical treatment decision-making. Similarly, non-surgical treatment decisions are typically made as soon as possible after surgery. Consequently, the data relevant to this theme was predominantly captured during participants' initial interviews when diagnosis and primary treatment were at the fore of women's experiences. That said, the final sub-theme explores how the study participants maintained ownership of decisions throughout the year post diagnosis even when a passive approach was adopted. Throughout this theme the findings are considered in relation to current Government policy and the debates highlighted in Chapter 1 (p.36-41) commencing with women's role in surgical treatment decision-making.

#### **5.3.1 Surgical treatment decision-making**

Though limited in terms of comparison the relatively low rates of passive involvement in treatment decision-making reported in previous quantitative research from 8% (Lam et al., 2003) to 13% (Janz, Wren, Copeland, Lowery, Goldfarb and Wilkins, 2004) would seem to contrast the current study findings. For those participants experiencing breast cancer for the first time a passive role was typically assumed in surgical treatment decision-making. This is illustrated in the following comments:

*'I think it was the doctor that made the decision (to have a mastectomy) because when I had the biopsy I had to wait for the results to come back*

*so I think they made the decision to have that'* (Elizabeth; Interview 1; Lines 36-38).

*'Well the doctor said it'll be a lumpectomy, it won't need to be a mastectomy because it's only small. They said what we do is we take the lump away and some of the lymph glands under your arm and they said you might have to come back if we find something in the lymph glands, come back for more treatment. I said whatever you think needs to be done do it'* (Fiona; Interview 1; Lines 72-76).

The speed at which diagnosis and surgical treatment were undertaken following referral to the symptomatic breast unit, as discussed more broadly by Charmaz (2002), may have influenced these women's compliance with treatment decisions. Furthermore, it could be argued that while already attempting to cope with the stress of diagnosis some participants may have opted to distance themselves from surgical treatment decisions as a means of positively coping with a situation where the possibilities for self-directed action are limited (Jadoulle et al., 2006). Research to date has largely neglected to consider women who have experienced previous breast disease (e.g. cysts), or had a family history of breast cancer without themselves experiencing cancer. This research found that these women took a more active role in making surgical decisions. This was the case for Jenny who opted to have a mastectomy following the deaths of two significant women in her life as a result of breast cancer.

*'The doctor said "well we'll do a lumpectomy" and it was my decision to say no and she (doctor) came out of theatre and said "right what are we doing?" and I said "take it off"'* (Jenny; Interview 1; Lines 87-90).

Post-surgical analysis of the breast tissue confirmed that a lumpectomy would have been an appropriate intervention for Jenny however she commented:

*'As it turned out they reckon I could have had a lumpectomy because my lymph nodes were clear but I couldn't take a chance. Right up until the last minute I could have changed my mind but I felt I was fighting it one hundred percent by doing that'* (Jenny; Interview 1; Lines 95-98).

During interview one, Sarah who was experiencing a recurrence of breast cancer described having made the decision some years previously to have a bilateral mastectomy if she were to be given the diagnosis for a second time.

*'There was no sense of shock, it was almost as if I sensed that this would happen, looking at my family history at some stage I knew I would have a re-occurrence (Lines 68-70). When you've gone through a process for eleven years you actually see an end and the only way I can describe it is it's almost like running a marathon, you hand the baton over and somebody gives you it back and says go and run it again but not the same journey, we'll give you a different route. So, it's almost as if I don't want to do it again eleven years on (Lines 45-49). I've spent a lot of time reflecting on my life and what I would do so the decision was made prior to me going'* (Sarah; Interview 1; Line 65).

Accordingly several participants perceived an active role in surgical treatment decision-making yet typically described being given the confidence to do so by the Consultant Surgeon. Linda, for example, requested a mastectomy though still sought approval to ensure that she was making the right decision.

*'Me and the doctor looked at it together and I asked him what do you think, do you think I'm making the right decision and he said yes, definitely and that really did it for me' (Interview 1; Lines 328-330).*

While Linda described herself as taking an active role in surgical decisions her desire for medical advice, facilitated by definition, a shared decision-making approach. Whether it is possible for women to take ownership of this process is debatable. Karnilowicz (2011) argues that ownership is delegated rather than negotiated with regards to treatment decision-making as ultimate control, power and responsibility are held by the healthcare provider.

### **5.3.2 Non-surgical treatment decision-making**

Irrespective of their perceived involvement in the surgical treatment decision-making process, all participants reported a passive role in making decisions regarding further treatments (e.g. chemotherapy, radiotherapy and adjuvant drug treatments).

*'I was told I needed the radiotherapy for follow-up and the team prescribed the Tamoxifen. They've prescribed and I've just accepted what they said. I don't ask questions, I just go along with it' (Lily; Interview 1; Lines 232-235).*

Greater preferences for passive involvement, up to 40% (Vogel et al., 2008), have been documented through quantitative research investigating unspecified breast cancer treatment decision-making. This suggests that the type of treatment decision may affect women's role in this process. However, following surgery women may be tired, may lack confidence or the resources to be as engaged as they would like (Mulcahy et al., 2010) which may contribute to the passivity reported in this sub-theme.

As discussed in Chapter 1, research focusing on non-surgical decision-making is sparse particularly utilising a qualitative methodology though the results of the present study support prior findings regarding older women's decisions concerning chemotherapy (Kreling et al., 2006). The women in the present study did not perceive a choice to participate in such decision-making and nor did the vast majority of women report a desire to do so. Participants cited the multidisciplinary team (MDT) and their Consultant as the decision-makers in the context of further treatments.

*'I think they have a multi-disciplinary team and I think they discussed the radiotherapy in the team meeting and they obviously considered that to be the best plan' (Susan; Interview 1; Lines 55-57).*

A recent UK based study analysed post-operative consultations in which twenty women who had undergone surgery for breast cancer discussed further treatment and subsequently interviewed both patient and practitioner regarding the decision-making experience (Mendick, Young, Holcombe & Salmon, 2010). The involvement of a multi-disciplinary team was described as providing reassurance that appropriate decisions were being made. Ellen also commented on the role of the MDT and her understanding of how decisions were made.

*'Apparently there it goes to a board and it's all discussed between everybody in this meeting. I was told that they would decide which was best. I was told that there were three things that could happen. I could have radiotherapy, I could have chemotherapy, I could be on Tamoxifen or I could be on a mixture of any of them. They tested everything that was taken away (breast tissue) and when I went back to see the breast*

*nurse she already had the prescription there waiting for me'* (Ellen; Interview 1; Lines 80-86).

Handing over control of treatment decisions to healthcare professionals was viewed in a positive manner and was rationalised in terms of the need for such decisions to be made quickly in order to receive timely medical intervention. This combined with the shock experienced at the time of diagnosis was perceived by many participants to limit their capacity to take a more active role.

*'I just said to her "I'll do whatever you think" because I was just that shocked I didn't know what to say. I just said to her "whatever you think is best just do because you know what you're doing"'* (Emma; Interview 1; Lines 18-20).

Developed from the coping literature of Lazarus and Folkman (1984) the model of emotional trade-off difficulty (Luce, 2005) purports that treatment decision-making, for example in relation to breast cancer, is influenced by a desire to cope with difficult trade-offs such as breast loss versus long-term survival. In choosing passivity participants avoided consideration of these trade-offs and the stress associated with making an autonomous decision when positive outcomes were not guaranteed. Furthermore, this research has highlighted that as in the qualitative research by Seale (2005) decisions to adopt a passive role in treatment decision-making were undertaken consciously, were one of choice and as such relinquishing control may be viewed as a positive coping strategy. Consequently, participants' actual level of involvement even though predominantly passive for both surgical and non-surgical treatment decisions would seem to be in accordance with their preferences. This contradicts research findings by, for example, Degner and colleagues (1997) who noted that over half of women do not attain their desired level of involvement. What is

more, despite adopting a passive role, participants continued to feel in control of the treatment decision-making experience as opposed to experiencing a loss of control given passivity as depicted by Halkett and colleagues (2007). Feeling able to ask questions and being responsible for their healthcare in terms of attending clinic appointments and adhering to treatment regimes were factors influencing this perception.

*'I could have questioned or argued but I chose not to because I felt that it was a decision to be made by professionals and a team of professionals, not just one person. Erm...but I think ultimately I decided whether to go through with the surgery and I decide whether to take the Tamoxifen each day'* (Pauline; Interview 1; Lines 217-221).

The following sub-theme focuses on the notion of maintaining control while enacting passive involvement in treatment decision-making.

### **5.3.3 Choosing passivity while maintaining ownership**

The concept of 'conscientious autonomy' (Kukla, 2005) can be used to aid understanding of the decisional involvement demonstrated through this research. The focus on ownership of, and commitment to, decisions as opposed to responsibility for making a decision suggests that a patient may describe accepting a clinician's decision without presenting as being passively compliant. Though many women in the current study may not have felt involved in the decision-making process (for surgical and/or adjuvant treatments) their choice for passivity did not characterise disengagement. Participants sought ownership of the decisions by stating, as in Pauline's previous quotation, that they could refuse treatment at any point. Moreover, finding justification for the decisions made and treatment regime itself, as well as being committed to completing the



treatment course supports the notion of ownership. Indeed, throughout the year following diagnosis participants continued to purport that their level of involvement had been apt given their individual circumstances and that appropriate treatment decisions had been made, frequently stating that they would take the same course of action again.

*'If I had to do it again I would have exactly the same. I cannot fault the doctor at all, in fact I think he's magic and if it was to come again I would want to go with him'* (Linda; Interview 3; Lines 107-109).

This satisfaction could extend beyond the healthcare trajectory as Sarah's reflection (following a recurrence) on undergoing a lumpectomy over ten years ago suggests that she continued to believe the decision to have been appropriate.

*'Strangely enough my sister-in-law had said "I think you should have had a mastectomy eleven years ago" and I said "why would you say that because it didn't come back in the same breast?" You know, so a lumpectomy was right at that time and I would say to any lady now, in fact one of my closest friends who comes with me, her sister-in-law's just been diagnosed and is having a lumpectomy and I would say if you can have a lumpectomy just have it. You may get eleven to twelve year or they may be fortunate and may never have another problem so I wouldn't say to go for the major surgery that I've chose'* (Sarah; Interview 1; Lines 575-583).

This was despite having consciously handed over decisional control to healthcare professionals at the time of her first diagnosis and more recently given a recurrence actively requesting a mastectomy. This is in contrast to the

findings of Thomas-MacLean (2004a) who reported that women continue to question decision-making once treatment has ended. Furthermore, as the present study did not identify discordance between women's desired and actual levels of involvement the decisional regret recorded elsewhere (e.g. Lantz et al., 2005) was not supported.

These findings hold clinical implications given the promotion of "shared decision-making" in the recent Government White Paper for Health (2010). Advocating "involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone" (p. 13) may reflect observations of positive long-term health outcomes (e.g. Anderson, Bowen, Morea, Stein & Baker, 2009) and greater compliance with medical regimes (Cameron, 1996) given patient involvement in decision-making. However, the findings within this theme suggest that not all women with breast cancer desire such involvement and make a choice in the early stages of their experience to take a passive role. Yet, these women retained a sense of control and ownership of treatment decisions and displayed a resolute satisfaction with the decisions made throughout the healthcare trajectory and into survivorship. Acceptance of and trust in medical opinions was crucial in facilitating decisions of passivity but as discussed in the following theme led to the seemingly long-term high satisfaction with treatment decisions.

#### **5.4 Acceptance of medical opinions**

Discussions pertaining to this theme initially emerged during the first interviews as women recounted their experiences of treatment decision-making. However, irrespective of the role in the treatment decision-making process, previous

medical history or treatment regime, participants' acceptance of medical opinions and trust in the expertise of healthcare professionals was unwavering throughout the reflections on their experience.

In the context of healthcare, trust is known to be a multifaceted construct (Berry, 2004) incorporating dimensions such as competence and honesty which are underpinned by perceptions of accuracy, knowledge and concern with welfare (Frewer, 2003 as cited in Berry, 2004). Participants frequently referred to the competence of the breast surgeons:

*'She (the breast surgeon) makes you feel.. .confidence, she makes you feel like she knows what she's doing.you couldn't be in much better hands than hers, she's one of the best in the country'* (Susan; Interview 1; Lines 209-211).

With regards to risk messages Paling (2003) highlights the necessity for medical professionals to portray both competence and a caring approach in order to engender trust. These elements were evident in participants' descriptions of their experience albeit in terms of differing healthcare professionals. In contrast to women's focus on the surgeon's abilities and experience, discourse regarding the breast care nurses was centred around their caring nature.

*'(The breast care nurse) was lovely, she was absolutely fantastic, talked us through it... she was just so professional, so.put your mind at rest and at ease'* (Laura; Interview 1; Lines 58...63-64).

As both parties were present at the time of each woman's diagnosis (with the breast care nurses remaining after the surgeon had left to address any

additional issues) the team as a whole were trusted to manage participants health needs.

*'They had my best interests at heart and I had to put my trust in the team to do their best...I trusted them to do the best possible job they could do'* (Gillian; Interview 1; Lines 125-128).

Such quotations sustain Moch's (1995) argument that the vulnerability experienced following a breast cancer diagnosis can lead women to hand over control of their bodies to healthcare professionals with the underlying hope that they will be well cared for. Similarly, women have been reported to adopt an external locus of control with regards to treatment decision-making referencing the expertise of healthcare professionals in order to aid management of the uncertainty associated with receiving a breast cancer diagnosis (Shaha et al., 2008). In support of such conclusions when asked about control over treatment decisions Laura commented:

*'You've got to put yourself in their hands. They are the professionals who know what's best for you and that's the route you've got to take'* (Laura; Interview 1; Lines 127-129).

This finding supports that of Temple and colleagues (2006) who identified doctor's advice as a key factor in women's breast cancer treatment decision-making. What is more, the implicit sense of trust enabled the majority of women in the present study to choose a passive role in surgical treatment decision-making. While Laura had initially proposed undergoing a mastectomy medical advice to the contrary led her to assume a passive role and accept medical advice.

*'When they did the operation they found out it was only tiny. Now, however many months on I think that it would have been a bit drastic. You know they're doing what's best for you'* (Laura; Interview 1; Lines 91-94).

Kukla (2005) argues that deferring to the expertise of healthcare professionals, as demonstrated in the previous quotations, is rational when an individual assesses practitioners to be better placed to make a medical treatment decision.

The passivity seen in relation to surgical treatment decisions extended to all participants for non-surgical decisions. This enabled these women to avoid additional anxiety and handing over control was perceived by all participants as ensuring smooth progression throughout the post-diagnosis phase of medical regimes.

*'It (treatment decision-making) was taken out of my hands but because of that it has all really flowed, everything's gone according to plan and according to timescales'* (Amanda; Interview 1; Lines 80-82).

Parallel to the present study patient's trust in the surgeon's expertise has been found to lead to an unquestioning attitude (Mendick et al., 2010) and being given a treatment plan facilitated greater confidence in the surgeon's abilities. When initial Consultant led surgical treatment decisions were found to be incongruous with histology results and subsequent surgical intervention was required participants described feeling shocked and distressed at this unexpected result. Moch (1995) notes that women may give their bodies and decision-making power over to those who are trusted or not trusted on the basis of a belief in the capabilities in the medical profession. The current study has

found that when this premise was flawed participants continued to trust the healthcare professionals. For three women a lumpectomy had been undertaken however a mastectomy was required shortly thereafter. Rather than this adversely influencing the trusting relationship previously established with the medical team Amanda commented on the expertise of her Consultant.

*'I was devastated because I was just getting used to the smiley scar underneath my boob which was very, very neat and I must admit she's fantastic at the job she does. Just shock and disbelief but I felt lucky to be truthful with you. I do feel lucky because if I hadn't gone and had the lumpectomy and if she hadn't taken the extra bit then who knows?'*

(Interview 1; Lines 88-93).

Similarly, Mary remarked:

*'That was a complete shock. I didn't expect that. I think if I'd have been told in the first place I'd have just gone with the flow so I just didn't expect her to tell me that but you know you either go along with what you're told or...well if you don't it's obvious isn't it'* (Interview 1; Lines 135-139).

Trusting healthcare professionals to maximise the chances of survival was frequently inferred in as participants contemplated the acceptance of medical opinions though rarely were issues of mortality explicitly faced in this context. Louise is the exception to this though the following quotation demonstrates her desire to accept only favourable medical opinions.

*'Well when he (Consultant Surgeon) said he would remove the lump and I would have twenty years to live, I thought well that's marvellous. When I was talking to the oncologist she said that it could come back to the same breast or it could come back to another part of the body, in another*

*place. It's not everyone it happens to so looking on the good side...I think the first version's better so I'll accept that. I'm just putting my life in their hands and trusting their experiences'* (Interview 1; Lines 125-131).

Women's ultimate reliance on healthcare professionals to eradicate breast cancer is discussed in the subsequent theme.

### **5.5 Getting rid of it**

The theme 'getting rid of it' is one of the few identified in women's longitudinal experience of breast cancer that is specific to one time point, that from diagnosis to surgical intervention. Consequently, as with the previous theme (acceptance of medical opinions), discussions relevant to this element of women's experiences were central to their initial interviews. However, once again, as this theme was so fundamental to women's experiences it was frequently reflected upon and echoed in successive interviews. Unquestionably, removal of the diseased breast tissue was of paramount importance to all participants and was spoken about repeatedly during the first interview.

*'My priority was to remove the problem, the cancer'* (Sarah; Interview 1; Line 85).

For several women an initial reaction was to request removal of the whole breast as doing so was perceived to maximise chances of survival.

*'I said if you think you're gonna have to take the breast off then just do it.*

*I said just get rid of it all and then I'll be alright'* (Fiona; Interview 1; Lines 78-80).

As reported in previous research (e.g. Katz et al., 2005) participants who did take a more active role in surgical decision-making did so by requesting a

mastectomy. However, contrary to previous qualitative research (e.g. Fang, Shu & Fetzer, 2011) for women in the present study the meaning of the breast was not perceived to be a key factor in the surgical decision-making process. However, echoing the work of Cassell (1976) participant's lexical choices as illustrated throughout this theme through references to breast cancer as "it" and "the cancer" and to breasts as "the breast" and "them" suggests an objectification of the body and the disease. This additionally indicates that women in this study viewed breast cancer as separate to the self and in doing so and in perceiving the body as a physiological system (Radley, 1996) were able to distance themselves from breast cancer. As theorised by Maclachan (2004) such distancing may be a self-protective coping mechanism to minimise stress and anxiety but also given participant's acceptance of and trust in medical opinions could reflect a desire to hand over responsibility for making decisions that will induce significant bodily changes. The choice of passive involvement in treatment decisions would seem to further support this notion. Accordingly, while Jenny took a more active stance in vocalising her desire for a mastectomy due to past experiences of cancer signifying death, removing the breast led to a decrease in stress by eliciting a sense of action.

*'Right up until the last minute I could change my mind but I felt I was fighting it one hundred percent by doing that (having a mastectomy). I just couldn't. my sister and partner both lost their lives and I just couldn't take that chance'* (Jenny; Interview 1; Lines 97-99).

This corroborates the findings of studies reporting that women fear cancer more than breast loss (Demir et al., 2008; Fallowfield & Hall, 1991). Women's priority of survival in order to fulfil responsibilities such as childrearing has been noted elsewhere (Fang et al., 2011) though was particularly evident in the current



study as women described the need to 'get rid of it' (whether via mastectomy or lumpectomy) to 'be around' for the sake of others.

*'If they got it away then that would be alright. I've got two children and a loving family. I've got them to consider' (Gillian; Interview 1; Lines 94-95).*

This finding may provide some support for the 'tend' response of the "tend-and-befriend" model (Taylor et al., 2000) (discussed in Chapter 3, p.80) as women engaged in such surgery in an attempt to protect their offspring and reduce distress. Laura, one of the youngest women in the sample, described initially requesting a bilateral mastectomy, her motivation being to enable her to watch her children grow up. Laura was however advised against this course of action by the Consultant Surgeon and she subsequently reflected on this decision-making process.

*'Initially, my reaction was just to get it taken off altogether, well both actually and I really wanted that...I really did. I've had my kids and I'm living my life and I just wanted to get rid of them both. I don't think it was a mental thing I was going through I just thought that was the best thing and then it'll never come back but the Consultant said that was far too drastic, it wasn't to that degree. She told me for a reason that I only needed a lumpectomy...so you do what they say don't you, you do what they think is right' (Interview 1; Lines 84-89).*

This further supports the previous findings regarding acceptance of medical opinions and women's conscious decision to assume passive involvement. Avoiding the need for further surgery and interventions were also reasons cited for wanting a mastectomy by, for example, Linda.

*'I've no chemotherapy, no radiotherapy, nothing because they've taken everything away' (Interview 1; Lines 192-193).*

Such findings within this theme concur with those of Collins and colleagues (2009) in that undergoing a mastectomy elicited some peace of mind and was seen to avoid the need for additional adjuvant therapies. Consequently, participants hoped that a return to normality would ensue shortly thereafter. Completing surgical intervention was clearly viewed as a milestone in this process.

*'You've got something in there, in your body that could kill you, take your life and until you get rid of that your life's not your own, how can it be?' (Jenny; Interview 2; Lines 177-179).*

This remained the case even for those participants facing several months of treatment.

*'I feel as though that's it, it's gone now, it's a case of just getting on with my life, getting sorted, so I can't wait for the chemo to end and then I can get back to normal' (Rose; Interview 1; Lines 63-65).*

This quotation also illustrates that once participants had undergone surgical intervention and the diseased breast tissue had been removed they no longer perceived themselves as having breast cancer. This is supported by the following reflection from Susan.

*'I believe at this moment in time I haven't got breast cancer in me. I think they got all of it out with the surgery and the treatments that have followed are just to make sure it doesn't come back' (Interview 1; Lines 127-129).*

Similarly, Sarah sought ultimate predictability (Frank, 1995) following a recurrence by taking control of her body and breast cancer through an active role in surgical decision-making.

*'I can say yes I'm in control of breast cancer because I haven't got any breasts but you don't know what the future holds in other ways, nobody does. I feel that breast cancer is behind me through the decision I made to have the double mastectomy. Without that I would never have been free of it'* (Sarah; Interview 1; Lines 628-632).

Perceiving the eradication of breast cancer at the point of surgery may have implications for how subsequent non-surgical treatment decisions are made and specifically may explain the increased passivity relating to such decisions as discussed previously in this chapter. Women's perceptions of breast cancer were additionally influential in treatment decision-making and form the basis of the following theme.

## **5.6 Cancer Schema**

Women's beliefs about breast cancer as well as information provision which influences understanding of the disease have been found to be influential in the treatment decision-making process (Halkett et al., 2005) and these aspects are discussed further in this theme. The participants prior knowledge and experiences of cancer were found to define their cancer schema (i.e. what they believe constitutes cancer (or not)) and these perceptions are discussed in the following sub-theme.

### 5.6.1 Perceptions of cancer

Participants' cancer schemas were evident throughout the data collection period and were found to influence these women's experiences of receiving the diagnosis of breast cancer as well as their psychological response to the disease. For Mary, whose husband had previously been diagnosed with cancer, this was evident prior to receiving her diagnosis.

*'They told us to come back to the waiting room and we could see that she was putting three chairs out and as soon as she put the three chairs out I said to my husband this is not good...three chairs is bad news...I knew someone would be sitting with me'* (Interview 1; Lines 58-60; 68).

Cancer schemas were also found to influence the process of accepting the breast cancer diagnosis as illustrated below.

*'I just felt like she had the wrong notes in her hand, sometimes even now I still do. I still think they've got it wrong because I felt fine. I wasn't aching, I wasn't tired, I was still at work full-time...there was nothing, so I really thought she had the wrong notes in her hand'* (Laura; Interview 1; Lines 37-40).

Disbelief was a prevalent reaction among participants experiencing cancer for the first time and was typically linked to a schema attributing physical symptoms and a limitation on activities of daily living to having breast cancer. Consequently, and as previously recorded by Lindwall and Bergbom (2009), feeling well at the time of diagnosis was linked to difficulties accepting having breast cancer.

*'It's quite frightening to think that you've got something growing in your body and you feel fit and healthy and it's hard to get your head round the*

*fact that it could kill you. You just feel like there's nothing wrong with you, you don't feel any pain or anything...its very strange. It was only when I had the operation that I didn't feel well and that's just like the recovery process and I think that's why it's hard to come to terms with really, that you have actually got breast cancer because you don't feel it'* (Gillian; Interview 1; Lines 362-368).

The following quotation taken from Laura's second interview further highlights this issue and the perception of being well until undergoing treatment regimes.

*'I wasn't tired, I wasn't sick, I wasn't losing weight. Sometimes I still think, I think about that all the time, it's not that that makes you ill, it's the treatment for it. So you feel like they're making you ill because I wasn't ill before, I was absolutely fine. It's such a strange disease or illness or whatever you wanna call it. It's quite scary that you have no effects, nothing at all until you find this little tiny lump but you never think for one minute that it's that because you feel so alright. You feel so normal, you don't feel anything'* (Laura; Interview 2; Lines 170-177).

While discussing their breast cancer diagnosis during interview one participants often reflected on schemas linked to aetiology and relayed a series of potential events leading up to their diagnosis.

*'We went to the Caribbean in 2002 and went on a cruise and it was hot, it were like 30 and when we came back it were like -3 in Manchester. From there we were both poorly until April. I had a boil on my back, never got shot of colds. I just wasn't well. From then onwards if I've done a job I've then sat down and gone ooph.as though I don't feel really well.and now I feel great. Last May we had a very bad accident.you*

*just don't know, you wonder what starts these things don't you...I don't know how the hell we got out alive but there wasn't even a scratch. The only thing that hurt was the strap across my chest, it really, really dug in and I just wonder, how do these things happen?' (Linda; Interview 1; Lines 123-132; 137-139).*

In discussing the results of a series of focus groups Wilkinson (2000) reported that individual participants used multiple versions to explain the aetiology of their breast cancer and relay a variety of potential causes. In addition, as is further exhibited by Linda's above quotation Wilkinson identified one of the most common lay explanations as being 'secondary to trauma or surgery' including a 'knock' to the breast. However, while Wilkinson found the most frequently mentioned cause of breast cancer to be reproduction/childbearing issues, interestingly, this rarely appeared in women's explanations of the origins of their breast cancer during the present research study.

An association between breast cancer and stressful life events was discussed in depth by several participants who cited divorce, bereavement, financial difficulties and work-related stress as potential contributors. The following extract from Louise's first interview highlights that such a conclusion was often reached when other lifestyle related risk factors had been discounted.

*'My husband left me twelve years ago, suddenly out of the blue.because we'd just bought this house and moved in on the February and in the April he said he's met somebody else and said I'm leaving and he just went' (Lines 183-186)...'I know inside my stomach was churning, thinking I was going to lose the house. That really worried me and that's the only thing I can think of. I mean I'm tee-total apart from*

*the office party once a year so it's not alcohol problems and my weight's alright.it's a mystery'* (Lines 199-201; Lines 204-205).

While comparison to quantitative research is limited, Lavery and Clarke (1996) found that 34% of a sample of 244 women with breast cancer focused on stress as a perceived cause. A more recent qualitative content analysis (Arman, Backman, Carlsson & Hamrin, 2006) of 118 interviews with women with varying stages of breast cancer reported that 71% of women perceived a link between their breast cancer and their life lived. This encompassed aspects of stress and other psychosocial factors such as bereavement, mental distress, and psychological trauma. As data collection progressed several women continued to reflect on the causes of their illness though subtle changes in the context of these discussions were noted. For instance, rather than discussing modifiable risk factors such as smoking and alcohol use as was undertaken in interview one, in subsequent interviews women began to focus on non-modifiable risk factors and alternate explanations. Mary, for example, considered her own schemas regarding possible contributing factors and like many women made reference to a genetic link though one that was interlinked with fate.

*'Sometimes I think the area we live in isn't good. If you look at other parts of the country they're probably not as high as us. I do think my stress had something to do with it. I'm not saying it caused it but I think it maybe had a contribution because my body was vulnerable. I do think some of its genetic; these things are destined from birth'* (Mary; Interview 3; Lines 151-155).

Consequently, women's sense of control over breast cancer and in turn the responsibility they assume for their breast health may be linked to the cancer schemas they hold. The research by Arman et al. (2006) described how 4% of

women believed heredity to be the sole genesis following a family history of breast cancer. However, while genetics were discussed extensively by the women in the current study who had experienced breast cancer within their families, a genetic predisposition with other contributing factors was often described as were current issues in genetic testing.

*'It's not conclusive but I left blood because apparently they need blood from somebody who's had breast cancer and if in the future they wish to do that test they can and of course my children have permission to use that if I'm not here. What I did find out, which was a contradiction from ten years ago, they told me it would only pass down the female side of the family but now they're now telling me it could pass down to my sons as well and down to their children so I've got two little granddaughters in that (moderate) risk bracket as well'* (Ellen; Interview 2; Lines 159-166).

The final theme in the study by Arman and colleagues (2006) reflects the rejection by some women of a link between breast cancer and one's life behaviours with a preference for believing in chance. This too was found by this research though such a conclusion was often the result of deliberation over the origins of cancer and women's previous cancer schemas which led to a distancing from such a possibility. For instance, participants who held a cancer schema attributing poor lifestyle with breast cancer now found this belief to be challenged and continued to question "why me?".

*'You've got all these people smoking, drinking, unhealthy eating and why have I got it?'* (Janet; Interview 1; Lines 188-189).

When such uncertainty arose, typically following a period of reflection, participants sought counsel from the breast care nurses which seemed to support the notion of chance.



*'I spoke to the breast care nurse and she said it doesn't discriminate; you're just unfortunate if you get it. It's as if you've had a sprinkling of magic dust and if it's landed on you you've got it' (Mary; Interview 3; Lines 149-151).*

Consequently, while many participants made reference to the biomedical risk factors discussed in Chapter 1 (p.13-15), with the exception of genetics, these risks were often rejected as possible causes of women's breast cancer. Instead, these women cited the influence of psychological factors and fate as influential in the aetiology of the disease thereby adding further complexity to current understandings of risk perceptions pertaining to breast cancer. The ways in which participants described breast cancer further provided an insight into their cancer schema and the psychological impact of their illness.

*'In my mind I saw it as a spider (breast cancer) and after I was diagnosed I actually had lots of horrible dreams about spiders. When I closed my eyes it was green and had lots of tentacles...I think when you're told it's gone to your lymph nodes, it's like where else has it gone, it's reaching out' (Amanda; Interview 1; Lines 174-177...183-184).*

The use of analogies and experiencing cancer-related dreams were most prevalent during the primary interviews as participants were attempting to understand the nature of their illness. Interestingly once Amanda had completed treatment she reported no longer having such dreams. The influence of healthcare professionals was often evident in such analogies.

*'She (breast care nurse) described it like a garden...I've had a dandelion removed, which is the tumour, and all the seeds of the dandelion have spread into the breast, which are the cells, so now we need weedkiller to*

*destroy all of the bad ones. I laughed, I thought well that explains it so much easier'* (Louise; Interview 1; Lines 76-81).

This quotation additionally highlights that the use of this strategy by the breast care team to facilitate women's understanding of treatments can be successful. Furthermore, the use of analogies by the breast nurses would seem to contrast the biomedical focus of the written information packs given to all of the study participants at diagnosis. The following sub-theme further considers women's informational needs with a specific focus on the management of information as a coping strategy to manage the stress of experiencing breast cancer.

#### **5.6.2 Managing information - access and sources**

Cancer schemas were modified with the acquisition of new information and all participants reported receiving verbal and written information about both breast cancer and relevant surgical procedures from the healthcare professionals involved in their care at the time of diagnosis. The provision of information that provides clear explanation of proposed treatments including risks and alternatives was central to the development of the Patient's Charter (Department of Health, 1992) and health communication has since become part of medical training in the UK. In 2003 Kreps highlighted the importance of effective health communication by suggesting direct links to cancer risks, incidence, morbidity and mortality as well as quality of life. A systematic review reported that healthcare professionals are the most frequently cited sources of information by individuals with cancer and those cancer patients rely on medical information packs and verbal communication from doctors particularly during the diagnostic and treatment phases of their experience (Rutten, Arora, Bakos, Aziz & Rowland, 2005). However, the review was not limited to papers

regarding breast cancer and the majority of primary studies did not utilise a UK population. In a study specific to breast cancer, giving women the choice of surgical intervention (mastectomy or lumpectomy) was not found to prevent psychiatric morbidity but "consulting style, in particular offering satisfactory information about treatment options was crucial to long-term adjustment" (Fallowfield, Hall, Maguire, Baum and A'Hern, 1994; p.203). While all participants described receiving verbal information including about potential treatment regimes, at the time of diagnosis hearing the word "cancer" was discussed by some of these women as limiting information processing capacity.

*'I think it was watching him (husband) that made me realise what she'd (Consultant Surgeon) said because I heard the word and I can honestly say I don't think I heard another word after that'* (Laura; Interview 1; Lines 49-51).

Attributing cancer to death was discussed as resulting in such a reaction and emotional state has been identified as a core issue in health communication (Edwards & Hugman, 1997 as cited in Berry, 2004). This may help to explain research findings purporting that women exhibit limited knowledge about the rates of recurrence and survival associated with differing surgical treatment options (Fagerlin, Lakhani, Lantz, Janz, Morrow, Schwartz et al., 2006). Women in the current study sought to minimise the extent to which such negative schemas prevailed in their psyche and instead focused on improving survival rates.

*'It's a scary word...it's like a death sentence...and really it's not any more is it? I think that's what needs re-educating, that it's not a death sentence any more. It's not like it was twenty years ago or even ten years ago.'*

*People are recovering, are being cured. I just wish they'd use another word, it's so scary. I still can't say the word'* (Laura; Interview 1; Lines 214-218).

The longitudinal nature of this research has enabled an insight into women's subsequent information decisions and highlights that many of the study participants used information avoidance and management as a coping strategy. The patient information pack providing general medical details regarding breast cancer and its treatment was recurrently considered to be anxiety provoking. This form of information designed to supplement verbal consultations is widely acknowledged as being beneficial in allowing patients to refer to relevant information away from the stressful environment of the consultation room (Berry, 2004). That said, information bringing negative cancer schemas to the fore was avoided by participants.

*'I've read through it but I don't like reading it because it just reminds you of what you've been through and what you've had. I think I've read through it once and then my son has had a look at it...I did read in there that you can get it in the other breast and I think that's put me off reading any more'* (Jenny; Interview 1; Lines 329-355).

Patient difficulties understanding medical information leaflets have been reported in the UK with readability and legibility being criticised (e.g. Payne, Large, Jarrett & Turner, 2000) yet the findings documented here suggest that it was not that women struggled to read and comprehend the information about breast cancer itself, it is that they did not want to do so. Accordingly, for numerous women in this sample, including Mary, the information pack received at the clinic at the time of diagnosis was set aside shortly after returning home. This supports the notion of escaping emotional triggers by avoidance of

information as previously reported in Lally's (2010) grounded theory study of women prior to first breast cancer treatment.

*'They gave me some books about breast cancer and I started to read them that day but then I think there's only so much you can face and so I put it to one side'* (Mary; Interview 1; Lines 96-98).

The cognitive-social health information-processing model (Miller, Shoda & Hurley, 1996) purports that individuals cognitively and emotionally process health information and describes a stable individual difference of monitor-blunting coping style as motivating health behaviours. Contrary to the information-seeking traits of monitors, blunTERS do not seek detailed information about their illness, find a large amount of information, particularly that including statistics, to be stressful and have a tendency to become overwhelmed by threatening information (Miller, 1995). The information avoidance demonstrated by numerous participants may suggest that they conform to the blunter style of coping. This finding also echoes those of Donovan-Kicken and Caughlin (2011) regarding topic avoidance though in the present study this was in relation to written information as opposed to verbal communications. With the passage of time several participants did reflect on facing a dilemma as while they did not want to read the medical information provided they felt that they should do so though did describe attempts to manage the quantity and content of their readings.

*'Well I tried not read it at first but then as time went on I thought I'd better be reading some of this. I must say I only read what I wanted to read. I didn't go into loads of details, I mean she was on the computer and was asking the doctors at work and I just read what I'd more or less been*

*given from the hospital. I didn't want too much detail'* (Margaret; Interview 3; Lines 145-149).

The information was returned to by many participants, including Janet, once surgery had been undertaken and decisions had been made regarding follow-up treatments.

*'They've given me loads of information which now I'm reading because when they first told me I put the books away in the drawer, I didn't want to think about it. Now I've had the operation I'm taking all the information in now'* (Interview 1; Lines 152-155).

In this context reading medical information was reported as reducing anxiety.

*'Well I'm sort of a worrier so really I don't like to know things because I know I'll worry about it. So when I read those leaflets it helped me a lot because it was comforting'* (Louise; Interview 2; Lines 112-114).

It is plausible that given the aforementioned finding that removal of the tumour was viewed as eradicating breast cancer that the participants were more able post-surgery to begin accepting the implications of their diagnosis. Moreover, by focusing on medical facts these women may have felt more able to prepare for upcoming medical regimes. This information management enables women to achieve some sense of control over their situation and lessen anxiety (Drageset et al., 2009). By contrast some participants continued to actively avoid information regarding the treatments being experienced in order to minimise concerns and the chances of side-effects occurring via psychological processes.

*'With the radiotherapy I didn't even look to what the side effects were gonna be because I think your mind...I think your mind's a wonderful thing but I also think it can be terrible. You see I knew what the side*

*effects were gonna be for the first part of the chemotherapy and I think you talk yourself into them. When I was going onto the tablets I didn't wanna know what the side effects were gonna be and so everything that happened...I haven't made it happen, the same with the radiotherapy'* (Mary; Interview 2; Lines 319-325).

Research indicates that information regarding treatment side-effects can result in patients attributing symptoms being experienced to listed side-effects however the likelihood of such adverse effects occurring is not increased (e.g. Raynor, 1998 as cited in Berry, 2004). Furthermore, in relation to chemotherapy while patient expectations can be predictive of subjective bodily experiences such as nervousness and nausea, this is not the case for objective toxicity experiences (e.g. vomiting and constipation) (Olver, Taylor & Whitford, 2005).

Knowing that they could contact the breast care nurses for advice and support provided reassurance for all women interviewed, whether they chose to do so or not. The following quotation from Ellen highlights this as well as the interaction between striving for survival, having trust in the medical team and treatment decision-making.

*'If it'll keep me alive I'll have anything. I honestly do have all of my faith in the team. I get so much information from them and they explain everything to me. I rang them about the pain in my arm and they reassured me about that. I do have faith that they know what's best and if they say taking Tamoxifen is the best treatment for me I would not argue about that'* (Ellen; Interview 1; Lines 267-271).

Several women disclosed giving the information to a family member to review as and when they felt it necessary, typically if they began experiencing treatment related side-effects.

*'My mam has the breast pack of mine and I say to her will you have a look to see if there's anything in there about your mouth ulcers whereas if I had the book in front of me I'd be thinking well I didn't have that but I've got it now. If you read it you get into your head that you've got it'* (Emma; Interview 1; Lines 261-265).

Consequently, for some participant's medical information, and adding to their cancer schema, was perceived to hinder their recovery and was consciously avoided though the social support elicited via this strategy is noteworthy. A step-by-step approach to knowledge acquisition was noted to occur by Drageset and colleagues (2009) in relation to the pre-treatment phase. The present study demonstrates that this approach was undertaken in the longer-term. The desire to remain positive may help to explain why these women undertook such information avoidance and rarely reviewed other treatment options and when doing so attached negative connotations to these treatments.

*'Some people can deal with that, having a mastectomy and having a false, but I couldn't have done that. You never really think about it until you talk about it but I think my breasts are a part of me as a woman. It's important to me as a person. I don't think I would feel a whole woman if I didn't have breasts and I still feel a little bit like because of the scars I've got on them but I've still got my breasts so it's the best of a bad thing.that's how I look at it'* (Margaret; Interview 1; Lines 228-234).

The myriad of issues regarding femininity and womanhood are discussed in the forthcoming chapter though negative perceptions of alternative treatments were additionally identified in relation to adjuvant therapies.

*'I was pleased to hear all I would need was radiotherapy and Tamoxifen. I was so glad I didn't need chemotherapy to tell you the truth...I didn't*



*want to lose my hair and have all the other side-effects associated with it'*  
(Lily; Interview 1; Lines 127-134).

These findings can be framed in relation to Festinger's (1957) theory of cognitive dissonance whereby women's management of information allowed them to avoid reflection on treatment decisions and in turn uncomfortable feelings of cognitive dissonance. Furthermore, in line with the aforementioned emotional trade-off model of Luce (2005) when making such difficult decisions the advantages of other treatment options would not be confronted in order to minimise potential stress. Coping through avoidance/distancing is typically deemed to be a negative coping strategy however it served a purpose for many participants and moreover the management of information access and flow would seem to represent a positive means of coping.

The importance of women's satisfaction with the information they receive about their breast cancer diagnosis and treatment can be demonstrated through its significant association with quality of life and both physical and social well-being (Davies, Kinman, Thomas & Bailey, 2008). Although a cross-sectional study relying on self-report data, similar findings have been reported elsewhere in that unmet needs for information about a cancer diagnosis have been linked to negative psychological outcomes including anxiety and depression (Mesters, van den Borne, De Boer & Pruyn, 2001). While women in the current study often chose to avoid and/or manage the flow of medical information only Ellen expressed dissatisfaction with regards to the quantity of information though this was specific to Tamoxifen. While direct comparisons are limited this appears to contradict the quantitative study of Temple and colleagues (2006) who reported that only 13.6% of women perceived that they had received their preferred

amount of information regarding surgical treatments. Nonetheless, for Ellen, the lack of information pertaining to the side-effects of Tamoxifen led to a sense of being unprepared and that this in turn had an impact on her family.

*'I think maybe had I been given a bit more warning about the side effects..they tend to play the side effects down. You know, I was told you've gone through the menopause, it's highly unlikely you'll feel any side effects at all, you'll just be fine and that's so not true. I've never spoken to anybody who's been on Tamoxifen who hasn't thought it was horrific. I think if I'd had a bit more information I think I might have been a little bit more prepared and I think the rest of the family might have been as well'* (Ellen; Interview 2; Lines 78-85).

Higher unmet needs for health information and emotional support have been shown to be associated with a greater likelihood of women consulting the Internet during the course of their illness (Lee & Hawkins, 2010). While the remaining women in the sample did not indicate being dissatisfied with the quantity or quality of information provided by the breast unit the Internet was utilised by over half of the study participants for the further acquisition of knowledge. This was despite them reporting being advised against doing so by the breast care nurses. Such information seeking behaviour commenced only after surgical intervention and, as illustrated below facilitated a more active role in further treatment decisions.

*'At the minute I'm researching all about reconstruction, all the different types of things you can have, what they do. So when I go I'll just say I don't need to come back to decide because I already know'* (Gillian, Interview 1; Lines 293-296).

Resisting being made to wait for information from healthcare professionals instead seeking answers to their own questions engendered a sense of control over participants' experiences, a process Sharf (2005) refers to as patient engagement. This corroborates the findings of Mulcahy and colleagues (2010) and illustrates a step away from traditional doctor-patient dynamics whereby the doctor acts as information keeper. This finding also suggests that some women do not wish to be fully dependent upon healthcare professionals and highlights their ability to develop coping strategies to manage the stress and uncertainty of having breast cancer as well as their desire for information about their bodies. Information seeking has previously been identified as playing a crucial role in women's efforts to cope with disruption to quality of life following a diagnosis of breast cancer (Arora, Johnson, Gustafson, McTavish, Hawkins & Pingree, 2002). For Sarah this monitoring coping mechanism (e.g. Miller, 1995) appeared when experiencing a recurrence as she moved from a previous avoidance of information to actively seeking to update her cancer schema.

*'Looking on the Internet. Whereas before I wouldn't read articles now I'm much more aware of watching and looking at new drugs that have come out and have become interested in drugs that haven't been licensed and an awareness of all of that. It's almost gaining information in case I need it for the future' (Sarah; Interview 1; Lines 540-544).*

Participants also sought, where possible, information and support from friends who had experienced breast cancer, a strategy which was perceived to be particularly beneficial.

*'When I had a pain in the top of my arm I thought ooh I wonder what that is so I asked a friend who'd had a mastectomy and she said oh don't worry, that's normal, you know, sort of thing so it's nice to be reassured*

*by people like that who've gone through it. I also had a magazine as well that they send you twice a year, MONA magazine and that's marvellous. Its people who are in the same position as you that have wrote in asking questions or for advice and then you realise that you're not on your own'* (Rose; Interview 2; Lines 265-272).

Reacting to a stressor through affiliation with groups who may aid the reduction of distress echoes the befriend component of the "tend-and-befriend" model outlined in Chapter 3 (p. 80) (Taylor et al., 2000). A recently published secondary analysis of interview data obtained from eighteen women with newly diagnosed breast cancer prior to breast surgery (Dickerson, Alqaissi, Underhill & Lally, 2011) provides further support for this sub-theme. The American research found that women accessed information from a variety of sources, including books, the Internet, and others who had experienced breast cancer, and that this was undertaken in accordance with a woman's individual need for information. Dickerson and colleagues further stated that women made attempts to control access to information to the self and to others however unlike the current study the use of others to achieve this was not reported. Likewise, the use of avoidance of information to minimise anxiety was illustrated via one participant's quotation though the specific timing of data collection prior to surgery and the lack of longitudinal design did not facilitate insight into women's use and non-use of information throughout the healthcare trajectory.

This theme has highlighted that participants held cancer schema even prior to diagnosis and that these schema were often factually inaccurate. Furthermore, while these schemas were modified throughout participants' experiences (given the input of healthcare professionals), many women avoided adding to their knowledge of the disease and relevant treatments. Irrespective of participants

strategies of information management women's cancer schemas influenced their responses to breast cancer throughout the year post diagnosis. This chapter has considered women's experiences of health-related decision-making and associated issues of control. The final theme continues this exploration through women's attributions of responsibility for their breast health.

### **5.7 Responsibility for breast health**

Discussions pertaining to control and responsibility for breast health were centred on breast self-examination. A lack of breast self-examination was reported both prior to diagnosis as well as in the initial few months post diagnosis when an active avoidance of checking breast tissue was frequently evident.

*'I mean I know I'm a trained nurse and have always known what you should do to check your breasts but at times I haven't. I was actually washing when I found it and it was quite prominent so it must have been there for some time.so I'm very wary of checking the other. Nobody expects they will get cancer, especially being a cancer nurse you know that anybody can get cancer but you never think it will happen to you'*  
(Lily; Interview 2; Lines 99-104).

Unrealistic optimism (Weinstein, 1983) featured in Lily's account though the fear of finding another breast lump constituted the primary reason provided for not checking the remaining breast/breast tissue. This suggests that participants utilised avoidance as a means to cope with the stress elicited by a breast cancer diagnosis. To some extent, bodily changes experienced during treatment regimes were viewed by Janet as limiting her previously vigilant behaviour instigated by prior breast disease.

*'I think I've always checked my breasts because for the last ten years I've been having mammograms because I've been having cysts so.but then again since this has happened I've never checked them. I think I've got that many chemicals in my body.I feel like my body's being poisoned, it's a horrible feeling and I've never checked them as such...In case I find another one. Now that's a funny attitude for me to have because I'm...I rub cream in this one for the scars but I never think I'm looking for lumps, I don't know why. I always used to do it regular before and I probably will do when it's all over and done with, the radiotherapy and everything and when I get back to normal'* (Janet; Interview 2; Lines 110-114; 118-122).

Accordingly, when these women were engaged in active hospital-based treatment assuming control and responsibility for the monitoring of breast health was offset by the reassurance of ongoing follow-up appointments. In particular, annual mammography screening and regular follow-up hospital appointments were critical in providing participants with the reassurance they sought.

*'Sometimes I'm too nervous to touch it in case there's anything there. I don't know yet, I don't think I'll check it yet. Well I'm getting checked through the hospital anyway so I feel quite relieved anyway, I'm gonna be having mammograms before the twelve months is up for that'* (Jenny; Interview 1; Lines 201-204).

In line with Frank's (1995) argument that the lack of focus on patient's bodily awareness in favour of diagnostic images and hospital checks is another way in which medicine encourages dissociation of the body and self. This may help to explain why the reassurance gained from follow-up was found to limit the extent

of women's breast self-examination despite their perception that greater breast vigilance was needed.

*P: 'I think you have two sides. You have the side where you know you should be more vigilant than you ever were before but I've also got this other side that says I don't ever wanna check them again because I don't wanna know. There's my sensible side that says check them and my silly side that says no don't'.*

*I: 'and which side wins?'*

*P: 'Probably my silly side at the moment because I'm still going to the hospital for checks and things' (Laura; Interview 3; Lines 199-208).*

Women have been found to have high expectations from follow-up as well as shortcomings in knowledge about recurrence and metastases (de Bock, Bonnema, Zwaan, van de Velde, Kievit & Stiggelbout, 2004). This cross-sectional survey conducted in the Netherlands identified factors including the prevention of breast cancer and hereditary factors and changes in the untreated breast as well as the long-term effects of treatment to be of central importance to women two to four years following breast cancer surgery. De Bock and colleagues reflected on the questionable effectiveness of follow-up particularly those including additional investigations and given improvements in adjuvant therapy. Yet the current research highlights that even for those women who were engaging in breast self-examination the ongoing trust in medical professionals, now to identify recurrence, was striking.

*'They checked both, even this one you know and even though I'm checking I'm pleased they're checking because I might miss it. A full examination and it makes me feel at ease because if there's anything*

*they'll pick it up, quicker than me. I can't feel anything but they might'*  
(Maria; Interview 2; Lines 232-235).

Supporting a previous UK study involving observations of breast cancer follow-up consultations (Beaver and Luker, 2005) participants expected that a physical examination would confirm or deny recurrence and when disease was not identified (either via breast examination or mammography) they felt reassured. However, detection of recurrent breast cancer is more likely to be identified by women themselves between hospital follow-up visits (Grunfeld et al., 1996). The findings of Beaver and Luker additionally indicated that healthcare professionals created an illusion that recurrences would be detected at a hospital follow-up (Beaver & Luker, 2005) as healthcare professionals continued to search for recurrence despite not expecting to discover recurrent breast disease. It is argued that this is indicative of the UK healthcare system fostering a reliance on follow-up appointments and in relation to the line of reasoning within this chapter would appear to extend the medicalisation of women's lives. Furthermore, the assurances of healthcare professionals while well intended may negatively impact on women's desire to resume control and responsibility over their healthcare, particularly those women who exhibit a reluctance to do so following completion of hospital-based treatments.

The following extract from Laura's third interview illustrates the challenge of regaining control over health while managing anxiety particularly once life was no longer focused on medical regimes.

*'Although you're thinking God I have to go to the hospital every day for twenty days...when it wasn't there it was the weirdest, insecure feeling I've ever had in my life I think. I think you've gone through these months*



*where your life's been surrounded by hospital and then it's a sudden stop and you're like God what now? I don't think I've seen anyone for about six weeks and it's the longest in a year that I've not been to the hospital, it's really strange. Part of me was glad obviously that it was all over with but I think it was time to start and get back to normal when you weren't surrounded by the hospital and everything...try as much as you can to get your life back. I think it's while you're going up and down there you know it's going away, it's getting better, they're treating it. Obviously you know it's not gonna go on forever and it comes to an end. I think it's because it so bluntly ends. I could feel myself getting more and more insecure and nervous as it was coming up to the time of it finishing and I expected to feel really relieved that it was over and I didn't. I totally shocked myself thinking "why do I feel like this, why do I feel so scared?" Obviously it's no joy going up and down there every day but it's that safety net'.*

*I: 'and that's been taken away...'*

*P: 'Yeah, suddenly it's not there. It's like this is me now, it's down to me. I remember saying before to you that you don't have any control over it at all because you're surrounded by hospital appointments and doctors and everything was going on in your head and you had no time and now there is time, it's down to me, it's up to me to get over it now' (Laura; Interview 3; Lines 11-45).*

This is further demonstrated through Joan's concern over the increasing time she faced between clinic appointments though she also refers to a perceived need to be vigilant yet keeping this under control.

*'It's a sign that you're making progress but you're unsure about being on your own with it but then with the increased vigilance you would hope that you yourself don't turn into a blithering idiot or a hypochondriac but at the same time are alert to finding something'* (Joan; Interview 3; Lines 195-199).

Ellen concurred that greater time between follow-up appointments represented recovery but highlighted that she was now also in a psychological state of readiness to take control of her healthcare.

*'I don't need reassurance so much now... I was ready psychologically to move to six months, never mind medically. It was good to make sure somebody was checking me out but now I've got things into perspective, I'm doing everything they're telling me to do and I feel much, much better in myself. So I'm moving through that process and six months was lovely to hear'* (Ellen; Interview 3; Lines 392...397-402).

In contrast to those participants who relied on the healthcare system to maintain control for their breast health, hyper-vigilance was an alternate reaction documented during the second and third interviews with some women reporting checking their breast tissue on a daily basis.

*'Well I have a shower every day and I always have a little feel, always have a little feel'* (Linda; Interview 3; Lines 239-240).

Likewise, Mary commented:

*'I mean I know normally before I would maybe have only checked them once or twice a month but now it's all the time. I'm petrified even though there's no breast there on this side I know you can still get cancer in the area'* (Mary; Interview 2; Lines 106-109).

Excessive breast self-examination, characterised as more than once per day, has previously been reported in a small subset (8%) of first degree relatives of women with newly diagnosed breast cancer (Epstein, Lin, Audrain, Stefanek, Rimer & Lerman, 1997). Such hyper-vigilant behaviour as opposed to avoidance has been found to more prevalent in at-risk women who report high cancer and general anxiety (Brain, Norman, Gray & Mansel, 1999). Research rarely considers women's experiences of breast self-examination post diagnosis. More commonly, the behaviours of women with a family history of the disease are the target for such research yet this has waned in recent years perhaps, as discussed in Chapter 1 (p. 21), given the controversy surrounding this method of screening. Using self-report questionnaires one study conducted in the USA has reported the breast self-examination practices of 345 breast cancer survivors four to eleven years post diagnosis (Trask, Pahl & Begeman, 2008). The study suggests that survivors do practice breast self-examination and that over 75% of the sample had self-examined within the previous thirty days. However, perceived barriers to conducting BSE influenced the frequency of this behaviour though the study did not consider hyper-vigilance and it may be that this manifests during the first year and wanes from this point. In the current study excessive vigilance through repeated checking of the breasts was perceived by Gillian to be potentially counterproductive.

*'I think you do it the point where you're trying to find something that's not even there. I think you need to put it to the back of your mind really and maybes every once a month, have a feel about and see if you can find anything and hopefully you don't' (Gillian; Interview 2; Lines 77-80).*

Becoming familiar with changes in breast tissue as a result of the treatments received in order to maximise the effectiveness of breast self-examination was described by Joan during a discussion regarding her increased vigilance.

*'I mean I'm examining the other one and getting used to this because there's quite a lumpy bit where the radiotherapy.. .you know. I'm getting used to what's normal for that particularly so from that point of view I think I do it more often, perhaps every week.have a look'* (Joan; Interview 3; Lines 160-164).

Where previously some participants had been anxious regarding checking their breasts having completed treatment for breast cancer functioned to reduce the sense of the unknown. Furthermore, these women's perception of the potential benefits of early detection facilitated greater vigilance.

*'I was frightened of doing it before but now I just do it automatically. I don't know I think it's just if you find something what will happen but now I've gone through it, I know what happens if you find something and I know I can cope with it. So the sooner I can find it, the sooner I can get on with dealing with it'* (Rose; Interview 3; Lines 169-170; 174-177).

Rose's quotation illustrates how breast cancer via monitoring breast health became a routine element of her life. Her continual use of 'I' additionally suggests that she perceived herself as having ultimate control and responsibility for her health and the management of illness. In discussing a conversation with another cancer sufferer Louise provided further insight into the anxiety women experienced when self-examining yet also depicts how confidence in the healthcare system to successfully treat breast cancer facilitated a change in her behaviour towards resuming responsibility.

*'So I said to her I know you have to check for lumps, before I got cancer and erm.I said I'm frightened now of checking the other one because.just in case it has come back in the other breast. Erm.but because the last few weeks because I know the radiotherapy has all clearing.I do now, I check my other one so I thought oh well I'm glad about that, that I'm not frightened of looking for any lumps now...Well I think because to me it was getting better the other.you know.the one with the lump, I think I thought if it comes back in other breast then I'm not gonna be rid of it, that you've still got it so when I was able to feel for lumps so I thought I'm glad about that. Then towards, well, the last day of the treatment talking to this lady I said to her that it wouldn't bother me if cancer did come back because I know it's treatable'* (Louise; Interview 3; Lines 223-228; 233-238).

Having undergone treatment for breast cancer Louise's quotation illustrates how the women's perception of themselves as being free of breast cancer and their continued trust in healthcare professionals influenced behaviour directed towards breast health. However, for participants who adopted a strategy of avoidance due to both anxiety and the reassurance of follow-up appointments it is plausible that conducting regular breast self-examination may have served to remind these women of their experience.

## **5.8 Chapter summary**

This chapter has demonstrated how for the women interviewed their lives became medicalised from symptom identification to early follow-up. Participants' high level of contact with the healthcare system during the months around diagnosis, treatment decision-making and surgical intervention is reflected in

this chapter with several themes being specific to this time period. Nevertheless, the longitudinal approach has additionally uncovered women's continuing rationalisation and satisfaction regarding the decisions made, including when a passive role had been adopted. Furthermore, this study design has revealed key aspects of women's experiences such as cancer schema and waiting that were prominent throughout the healthcare trajectory and even prior to diagnosis.

The study participants were often found to delay help-seeking behaviour for a breast symptom frequently citing caring responsibilities, pre-organised events and their cancer schema, as evidenced through a lack of symptoms, as reasons for this behaviour. However, the negative connotations these women assigned to delaying obtaining a medical opinion in conjunction with their cancer schema suggests that fear of mortality and cancer anxiety relating to a medicalised existence were influential in their wait.

Participants' subsequent attempts to manage the stress of being diagnosed with breast cancer led them to draw on their cancer schemas to facilitate treatment decision-making. While participants with a history or family history of either prior breast disease or cancer perceived themselves to have had an active role in surgical treatment decision-making their reliance on medical opinion suggests a shared approach was taken. Furthermore, the majority of participants chose to be passive in this process and this extended to non-surgical treatment decisions. This passivity was underpinned by acceptance of medical opinions and trust in the expertise of the breast surgeons to rid them of breast cancer. Nevertheless these women retained ownership of decisions and were not disengaged from the decision-making process. It is also possible that the

observed differences in levels of involvement in surgical and non-surgical decision-making reflect the tangible nature of the differing treatments.

All women interviewed described waiting for normality as their lives became medicalised revolving around hospital appointments and treatment regimes. This drive to return to a previous state of normality with a focus on diagnostic tests and medical regimes is suggestive of women adhering to Frank's (1995) restitution narrative type. However, while Frank states that a key component of this is the move from health to illness and back again even through the longitudinal nature of this study the return to normality was not always identified one year post diagnosis. Undergoing treatment for breast cancer had an effect on participants' activities of daily living including employment and had financial implications leading to several women returning to work before adequate recovery was attained. Moreover, such changes resulted in participants relinquishing identities, particularly those aligned with womanhood, and elicited change to their sense of self.

While these women desired a 'restored' self, the frequently unanticipated long-term impact of medical regimes made disengaging from a medicalised existence difficult even once hospital-based treatment had been completed. Women's long-term reliance on healthcare professionals for reassurance was seen across the sample yet while hyper-vigilance over breast self-examination was commonly observed by contrast for some participants the consequence was limited personal responsibility for breast health. This can once again be linked to the combination of fear, uncertainty and trust in medical teams and procedures. The strategy of avoidance may be further explained, at least in part, by participants' ongoing struggles to accept changes to the body and self.

The impact of breast cancer on women's bodies is the focus of the following chapter.



## **CHAPTER 6: THE BODY**

### **6.1 Introduction**

The ensuing chapter is separated into three parts, the first focuses on participants' perceptions of their body encompassing themes relating to the meaning of women's breasts and how this emerged during women's initial interviews through rationalisations of breast surgery to breast loss. Transitions from a healthy to an ill body are discussed in themes considering the long-term impact of physical limitations on participants' self and identity and the enduring influence of treatment side-effects on women's perceptions of their external appearance. The second section of this chapter considers the strategies women adopted to manage changes in the body from immediately post-surgery to those experienced as breast cancer treatment progressed and beyond to one year post diagnosis. The longitudinal management of changes resultant to breast surgery comprises themes focusing on women's experiences of using external breast prostheses and associated changes in dressing behaviour. Management of chemotherapy-induced alopecia and the use of complementary therapies to manage treatment-induced side-effects are also themes in this section. The final component and theme of this chapter explores how women's bodies and the long-term management of their appearance served as a permanent reminder of breast cancer.

### **Part 1 - Body perceptions**

The themes detailed in this first part of the chapter focus on participants' perceptions of their body and how these perceptions changed throughout the year following diagnosis as a result of breast cancer treatments. To begin, the

meanings these women associated with their breasts are discussed and their perceptions of both the necessity and conversely the non-importance of their breasts are represented.

## **6.2 Rationalising breast surgery through the meaning of the breast**

Irrespective of their role in the treatment decision-making process all women interviewed rationalised the need for their specific breast surgery and perceptions of their breasts were integrated in these accounts. Given the recency of treatment decision-making this was primarily a feature of the women's initial interviews. For participants who had undergone a mastectomy a medicalisation of the breast was evident, as previously documented by Langellier and Sullivan (1998), with these women placing an emphasis on breasts being an external organ that was no longer needed.

*'I lost my husband seven and a half years ago and it would have been an impact had he still been alive but I know this is just an organ outside the body. Everything else is functional and it's not gonna make a big difference to my life in the future. I'm not looking for another partner though I do have a friend who lost a breast, went on the Internet, married a lovely fella on it and they're very happy since (laughing) but I'm not really looking in that sense. I'll not get married again so it doesn't matter'* (Lily; Interview 1; Lines 157-163).

For several women breasts were no longer considered a necessity once child-rearing had been completed and/or when women were either in a stable long-term relationship or conversely did not anticipate having an intimate relationship in the future. Moreover, reinforcing the notion that breast loss does not limit

activities of daily living and rationalising in relation to survival were prominent in participants' discussions on this issue.

*'You look different...but I am what I am because of what goes on in my head. When I have a prosthesis in nobody knows any different when I'm out. I haven't had any problems. It's an appendage that at my age I'm not going to need. It's not like having stomach cancer or lung cancer where losing a part can impede on your life. I can get back to doing what I did before. Nobody will have any idea that I have lost my breasts. I think the days of thinking about being a page three model went a long time ago. I would rather lose the whole breast and get rid of the cancer. I still feel like a woman, it hasn't taken away my feeling of being feminine'* (Susan; Interview 1; Lines 140-148).

Sarah described having similar feelings though reflected that these perceptions and her desire to have a bilateral mastectomy had only emerged following her previous breast cancer diagnosis.

*'I think again it's about maturity, about recognising that yes breasts are a very important part of a female body but to be alive is even more important than having a pair of breasts. It's survival really, it's your own mortality that you've looked at and then it becomes more important and you know, the cosmetic side of life comes second'* (Sarah; Interview 1; Lines 274-278).

These results are supportive of previous findings indicating that survival is of paramount importance to women (e.g. Fang et al., 2011). However, paradoxically perceptions of breasts as not being a necessity may be one explanation as to why some women do not conduct breast self-examination or

do so infrequently. Nonetheless, the meaning of an individual participant's breasts heavily influenced her adjustment to breast loss. For Gillian needing to have her breast removed was particularly distressing and she struggled considerably post-surgery to accept this loss.

*'Someone who couldn't drag themselves out of bed on a morning I think, just thinking my life would be over and I couldn't face anybody. I think that's how I imagined myself to be before I had my operation. I couldn't see life beyond having a mastectomy but it's surprising how you come to terms with things. At the end of the day I haven't lost a leg or an arm or anything that would stop me from doing a lot of things. Its more...I think it's a vanity thing' (Gillian; Interview 1; Lines 225-231).*

Similar to findings by Fang et al. (2011) Gillian persuaded herself to accept mastectomy as illustrated through her rationalisations, and knowledge of post-mastectomy alternatives were discussed as alleviating some of the negative impact of breast loss. The prospect of rebuilding her body through reconstructive surgery and avoiding delays in this procedure was of central importance to Gillian.

*'The majority of the time I'm pretty alright with it really, especially more so now as I know I don't have to have chemo or radiotherapy, which would have meant my reconstruction would have been a long way away. Now, it's only a matter of months away' (Gillian; Interview 1; Lines 186-190).*

The knowledge that reconstruction was possible also reinforced Amanda's rationalisation for having a mastectomy.

*'I've felt more for how my husband's been feeling about it than myself because it's happened, it's like that. It wasn't pleasant when the bandages came off but as long as it didn't bother him then it didn't bother me. Like the breast care nurse said, it's something you can have re-built, it's not as if it's your liver or your heart, it's not a vital internal organ and I think she's right'* (Amanda; Interview 1; Lines 294-299).

The above quotation supports the opinions of Young (1992) by revealing the role of the breast care nurse in nurturing a medicalised view of breasts as being objects that are replaceable. Amanda's extract additionally highlights the importance of women's partners in promoting their psychological well-being through attachment validation (Bertero & Wilmoth, 2007). This aspect of self that emerged through a meta-synthesis refers to validation from women's partners that they are loved regardless of a changed body.

Unlike the findings of Fang and colleagues (2011) this research study has found that such rationalising was also undertaken when lumpectomy was conducted. Perhaps this served as a means through which women could regain some control over the surgical treatment decision-making process. Importantly these rationalisations were made in the context of the meaning of women's breasts specifically their symbolic nature and links to womanhood and femininity.

*'Some people can deal with that, having a mastectomy and having a false breast, but I couldn't have done that. You never really think about it until you talk about it but I think my breasts are a part of me as a woman. It's important to me as a person. I don't think I would feel a whole woman if I didn't have breasts and I still feel a little bit like because of the scars*

*I've got on them but I've still got my breasts so it's the best of a bad thing.that's how I look at it'* (Margaret; Interview 1; Lines 228-234).

Similarly, Louise opened up about her fears of breast loss, a finding that was formerly described in the Turkish phenomenological study of Demir and colleagues (2008) albeit from a sample of women pre-diagnosis.

*'I think the fear of the breast not being there sort of thing.it could be vanity but I wasn't really looking forward to having a false breast there'* (Louise; Interview 1; Lines 220-222).

Louise's quotation suggests that had a mastectomy been required an alternative would have been sought yet that this would equally have elicited a negative reaction. Accordingly, in support of the writings of previous authors (e.g. Wilmoth et al., 2004) participants' breasts were consistently aligned with meaning related to femininity, womanhood, child-rearing and as part of a sexual relationship. This corresponds to the representation of the 'functional' and 'gendered' notions of breasts derived by Langellier and Sullivan (1998). These meanings as revealed through women's rationalisations represent efforts to cope with whichever breast surgery had to be undertaken. As reviewed in Chapter 2 (p.60-65), mastectomy has been reported as resulting in an altered body image (e.g. Kunkel et al., 2002; Lindwall & Bergbom, 2009). The following theme discusses the impact of this surgical intervention as experienced by the women in the present study.

### **6.3 Breast loss**

For those participants who did undergo mastectomy breast loss had both physical and psychological consequences that became apparent even before the women left hospital.

*'I didn't dare look at it and erm.they came in on the Tuesday to change the dressing and I just looked at the ceiling, I didn't want to look but on the Wednesday I was talking to a nurse off the ward. I already know her personally and she sat with me and helped me. She took my dressing off and helped me come to terms with looking at it and I was shocked at what it looked like because I really didn't know what to expect and the pictures you get in a book.it doesn't really show you does it, it's a drawing isn't it, it's not a picture. So, I didn't really know what to expect and of course it was all swollen and sore and I found it quite distressing'* (Mary; Interview 1; Lines 179-187).

Participants continued to discuss the impact of breast loss during the second interviews once they had begun to reflect upon their changed bodies though focused more on their physical appearance as opposed to rationalising and accepting breast surgery. Linda was one of the few women to describe increasing pain and discomfort directly related to the chest.

*'I miss my bust, I'll be honest with you.you know like I get a sore.well it must be bone and it gets a bit sore there, I'm gonna mention it to him when I go next time but I think it's like when you lean on the chair and things and when you're in bed on a night instead of rolling onto your bust you roll more onto the bone'* (Linda; Interview 2; Lines 66-70).

Participants' accounts demonstrate a grief for the loss of their breast and as in previous research findings (e.g. Thomas-McLean, 2005) women described having to cope with changes to their body shape including a loss of symmetry, hollowness in the chest wall and scarring.

*'I always feel lop-sided'* (Lily; Interview 2; Line 142).

*'I'm actually very scooped out even where the breastbone is it's not the same on either side. I mean mine is really, really hollow' (Amanda; Interview 2; Lines 233-235).*

The impact on this participant's body image was unmistakable.

*'It looks horrible, absolutely horrible. One's missing and...I feel a bit freakish. I suppose I'm still getting used to it' (Jenny; Interview 2; Lines 127-128).*

Two women underwent bilateral mastectomies and while this was deemed to make adjusting to a changed body image easier than experiencing a loss of symmetry the impact on women's body shape had an ongoing psychological impact.

*'I think the fact that I have no breasts makes it easier than just having one. My body shape seems very different to what it was before and adjusting to that is a difficult thing' (Sarah; Interview 2; Lines 265-267).*

Susan, who underwent the second mastectomy shortly after her first interview, additionally discussed having a bilateral mastectomy in relation to her sense of femininity.

*'When I look at myself I don't really look very much like a woman. If you see me minus these (prostheses), if you were to see me erm.sort of naked from the waist up if you like I feel very much like I have lost my feminine identity. That isn't...it doesn't look...it's a funny thing because I don't get desperately upset by it because it doesn't actually look ugly, the scars are very neat and it looks fine. Obviously they're still quite new wounds so they're gonna settle down a lot and I appreciate that, I*



*just.because I haven't got breasts any more I don't look like a woman*  
(Susan; Interview 2; Lines 118-125).

Accordingly, in support of previous qualitative research breast loss and the associated altered bodily appearance led participants to question their femininity and womanhood thereby disrupting identity (McCann et al., 2010) and affecting their sense of self requiring them to re-define the self (Bertero & Wilmoth, 2007).

The negative emotional change resultant to Jenny's changed body is demonstrated in the following extract from her first interview.

*P: 'I don't ever, ever expect to find another partner...*

*I: because you've had a mastectomy?*

*P: Yeah. How I look.well right now I don't ever want anyone to see me naked, ooh God no, absolutely not'* (Jenny; Interview 1; Lines 232-237).

Disturbances associated with women's sexuality are widely reported particularly during the first year post diagnosis (e.g. Emilee et al., 2010) though like other women Jenny subsequently hoped that the passage of time would aid adjustment to her changed body.

*'Maybe one day I will be used to it'* (Jenny; Interview 2; Lines 128-129).

In adopting a longitudinal approach further exploration of these feelings was possible during the subsequent interview and indeed in her final interview Jenny reflected on coping with her changed body.

*'I haven't felt very emotional about myself since the first interview after I came out of hospital and I couldn't even look at myself could I? It doesn't really bother me now. It feels quite funny because it's hard, on the chest*

*and it's funny to feel but it doesn't upset me as much as it used to and hopefully it'll just get better'* (Jenny; Interview 3; Lines 218-222).

The use of "it" to describe the absent breast was prevalent in participants' accounts of their experience and can be observed in many of the quotations used to substantiate this theme. A difficulty finding words to describe the post-mastectomy body was previously noted by Manderson and Stirling (2007) though interesting the present study has found this to be prevalent throughout the year following diagnosis. This in itself may be an indicator that some women experience long-term disruption to their relationship with their body.

To provide an alternate perspective, for several women breast surgery (partial breast loss and to a lesser extent mastectomy) did not induce the feeling of losing femininity that they had anticipated and instead they reflected on womanhood as being beyond the physical body.

*'I think breasts are a part of being feminine, or that's how I've always looked at it. As I say I've always tried to keep myself trim and looking okay and now I've had it done and I'm thinking well...it's not actually. I still feel like a woman and I still feel feminine'* (Janet; Interview 1; Lines 258-261).

The women participating in this research study rarely spoke of cancer in relation to breast loss and did not discuss breast surgery including mastectomy in terms of representing an unhealthy body. Instead, the physical limitations that emerged as a result of having breast surgery and partaking in and managing the side-effects of subsequent prescribed treatment regimes were associated with gaining an illness identity.

#### 6.4 Physical limitations: losing a healthy identity

As discussed in the previous chapter in relation to a medicalised existence, participants craved and waited for normality. With regards to the body this typically began in the post-surgical recovery period when the impact on the body, habits and activities of daily living became so apparent that these women's sense of self became altered (Charmaz, 2002).

*'I don't know really it's such a shock because I've been so fit, I never stop. When I'm at work I come home and go to my daughters and take her dog out and do some painting but not now, I can't do anything'* (Elizabeth; Interview 1; Lines 24-26).

Elizabeth's quotation highlights how during times of illness individuals focus on physical activities (Leventhal, Idler & Leventhal, 1999) as bodily limitations distorted body-self relations. Women's way of being in the world altered with a loss of self-integration (Gadow, 1980) as breast cancer treatment restricted their world and led to a separation from their previous way of life and former identity. The illness and treatment side-effects such as pain and fatigue that were experienced from as early as the first interviews and which for many women persisted throughout the data collection period were perceived to constitute a lack of normality and suggest an alienation from the body.

*'What isn't normal is the aches and pains, the tiredness...I mean I've had to slow down and sometimes I have to rest and stop what I'm doing which is quite annoying but it's because I'm tired. It slows you down a little bit'* (Amanda; Interview 1; Lines 248...269-271).

Pain was a commonly reported side-effect, due to lymph node removal and contributed to a sense of losing a healthy identity and associated normality,

particularly at time one as women were recovering from the immediate effects of surgery.

*'I get quite a lot of pain in my arm from where they took the lymph nodes. I've got quite severe pain right the way down to my wrist so periodically that'll pull me up and when it does it jolts me back into, oh my God'* (Ellen; Interview 1; Lines 180-183).

Feelings of frustration as a result of physical limitations were evident in women's accounts of their experience particularly in the weeks following surgery and this focus suggests a lack of agency regarding the body.

*'A little tired and a little frustrated at the things that I can't do. My arm's doing really well I think but there are still things like I can't peg the washing out because I can't stretch without quite nasty pain'* (Pauline; Interview 1; Lines 273-275).

Frustration at bodily limitations remained evident during women's second interviews.

*'I do feel more tired. I'm a very energetic person but I find that I can't do as much before I'm tired and I get frustrated because I haven't got the strength in my arm that I had and I've found that really, really frustrating because I've got to pace myself'* (Pauline; Interview 2; Lines 57-60).

Several authors (e.g. Corbin & Strauss, 1988) argue that a new self-concept arises from accepting bodily limitations and from the new way of acting in the world. The women in the current study had no choice but to accept some level of change during the first few months post diagnosis, change which threatened their self and identity.

*'That can get to you, that can get you down I will admit, not being able to do your everyday tasks, your housework. People say you should be glad of it and you are because you can't do it but at the same time, well for me I felt as if I was not being myself because I couldn't do it'* (Maria; Interview 2; Lines 216-220).

As illustrated, physical restrictions during this time led to participants being unable to carry out traditional gendered roles such as housework. Handing over control of their roles was described as distressing for these women and accordingly taking back relevant tasks signified some return to normality. The disruption of the relationship with the body leads to one of Frank's (1995) acknowledged problems of embodiment - lost control. Seeking normality to regain control over life following a diagnosis of breast cancer supports the review of Bertero and Wilmoth (2007). The longitudinal approach adopted in the present study has additionally revealed that this search for normality (in a physical sense) began immediately following breast surgery. It was, however, particularly notable during participants' second interviews as adjuvant therapies were undertaken. Yet, despite the fact that participants recognised their limitations the following quotation from Gillian portrays the hope that these would not be permanent.

*'I still get quite a bit of pain sort of under my arm and in my arm. They've told me it's just time, a time thing, it'll get better in time and just. I think you need to know your limitations'* (Gillian; Interview 2; Lines 272-276).

Consequently, although participants adopted a "transitional identity" of an individual temporarily afflicted by illness (Clarke & James, 2003) they did not, at least initially, contemplate long-term change. The majority of participants

continued to strive for physical recovery and the potential for such an occurrence is acknowledged in the model of Morse (1997) who views this as preceding acceptance of bodily limitations and an altered self. Research focusing on fatigue following a breast cancer diagnosis is relatively limited and dominated by quantitative studies of association using self-report measures. One of the few qualitative interview studies exploring the fatigue experiences of older Taiwanese women with breast cancer discussed the impact of emotions and treatment side-effects on fatigue (Tsai, Lin, Chao & Lin, 2010). The research reported women's perception that fatigue was a normal reaction to breast cancer given uncertainty and stress, one that they were embarrassed to share with others. One finding that it did not report however was the difficulties experienced in deciphering the origin of fatigue. Rose reflected on how she may have misinterpreted potential symptoms, predominantly fatigue, and felt that she needed to learn to listen to her body once again which suggests a loss of confidence in the body.

*'When I think about how I was before, I was quite tired before. I used to come home on an afternoon and just shut my eyes for ten or fifteen minutes and then I'd be fine. You put that down to age but then you wonder if that was one of the telltale signs, feeling a bit tired. I suppose that's the problem really when you get into your fifties you put a lot down to age and you don't know what your body's telling you really'* (Rose; Interview 2; Lines 159-164).

Symptoms of pain and fatigue typically prevailed throughout the data collection period influencing participants' physical and psychological well-being. Such findings for those women who had chemotherapy supports the conclusions of Engel and colleagues (2004) who reported long-term psychological

consequences given the joint effect of chemotherapy and breast surgery. Equally, however, participants who did not undergo chemotherapy continued to experience these issues.

*'I do soon get tired. When I said to the doctor she said what do you expect so...and that's what I don't like, the soon getting tired. I like to be able to get up and go' (Linda; Interview 3; Lines 156-158).*

Research suggests that women may continue to experience fatigue up to sixteen months after completing breast cancer treatment (Thompson, 2007) which may help to explain why women often considered it's presence as an ongoing symbol of illness. Furthermore, while participants had anticipated regaining physical health within the year from diagnosis as highlighted by Susan this was often not the case.

*'I'm not thinking of myself as a cancer patient, I'm thinking of myself as a woman who should be back doing what she was doing and hasn't got there yet' (Susan; Interview 3; Lines 75-77).*

The above quotation suggests that while Susan perceived some return to normality in no longer being a woman with breast cancer she demonstrates conflict in referring to an ongoing wait for a return to her previous healthy identity. This supports the notion that women hope even up to a year on from diagnosis that returning to their former life and self remained a possibility whether this was feasible or not. Integral to this longer term change was the impact on the body of non-surgical treatment regimes. All participants were prescribed at least one treatment in addition to surgical intervention and the majority of women interviewed underwent a combination of therapies. The following theme illustrates how treatment side-effects were perceived to be

signs of ill health and consequently led to participants primarily viewing themselves in terms of illness.

### **6.5 Treatment side-effects as signs of illness**

For many participants, the onset of treatment-induced symptoms in conjunction with generalised physical limitations, as discussed in the previous theme, was perceived to be the point at which the body began displaying signs of illness. Accordingly, this point in time signified the transition from a healthy to an ill body, self and identity. The present theme considers women's experiences of treatment side-effects as signs of illness and is divided into several sub-themes pertaining to differing treatment(s)/side-effects. The impact of chemotherapy was particularly evident and resulted in women replacing the transitional illness identity seen post-surgery and accepting that longer-term change was inevitable. Given the treatment timeline participants typically raised these issues during the second interviews when active hospital-based treatments were significantly underway.

#### **6.5.1 Chemotherapy-induced nausea and fatigue**

The physical impact of chemotherapy is widely reported and research exploring psychological effects pertaining to, for example, reduced social participation and more generally decreased quality of life is becoming increasingly evident (Turgay et al., 2008). Even prior to commencing chemotherapy participants reflected on the potential impact of this intervention perceiving side-effects, specifically nausea, to have the greatest potential to challenge their abilities to cope with breast cancer.



*'Really only the sickness bothers me. (The doctor) said it might only last two days but she said we'll find a sickness drug that helps you. I know I'll be lethargic, tired, that could be a side effect but I think once the sickness goes I can cope with the tiredness'* (Louise; Interview 1; Lines 271-274).

The following extracts capture how once chemotherapy was underway participants began to detach the body from the self (e.g. Radley, 1994) as the body became dysfunctional and unfamiliar. In accordance with Frank's (1995) disciplined body the quotations suggest a dissociation with regards to embodiment however contrary to Frank's notion of body-relatedness these women exhibited a heightened awareness of, and attention to, their bodies.

*'I see what they're putting inside me and that's around your body and I've got to...you're weeing it out and its obviously killing your blood cells because your hair's falling out and I'm bloated up. I just don't feel as if this body's mine at the moment because I was quite fit beforehand'* (Janet; Interview 2; Lines 145-148).

Consequently, these women had moved from a state of perceived good health immediately prior to diagnosis to a position wherein, as discussed in the previous chapter, the body had become subject to medical regimes, interventions that were now resulting in an unhealthy identity.

*'When I looked in the mirror the other day I thought I look as if I have got cancer because my hair's gone, I've got that pasty look and the bloated look and I think it's the first time I've thought you look as if you've had it or you've got it'* (Janet; Interview 2; Lines 169-172).

The discrepancy between undergoing treatment(s) designed to re-establish a healthy identity which, as discussed previously in relation to 'getting rid of it', participants believed had already returned (doing so following surgery) seemingly influenced perceptions of this aspect of women's experience. Nausea and fatigue were reported as key issues for all participants undergoing chemotherapy and were symptoms that influenced their daily lives throughout the treatment course.

*'Every night I keep thinking of the chemotherapy and all the injections. I noticed, I haven't said it to anybody because when you go to chemotherapy you forget about things...sleeping patterns...I seem as if I'm tossing and turning all night. I don't seem as if I'm getting a comfortable night's sleep. I mean I do because I haven't been as tired as the first session...you know, I was very tired. The last two I haven't been falling asleep like I was with the first one so I'm obviously getting the sleep but whether it's with sort of thinking about the chemotherapy every night that I feel as though. I think also when you sleep on your side your stomach feels all uncomfortable, so it's probably that and then when you turn over you get the same again. Then when you sleep on your back it seems as though your stomach draws into you, which makes it not so comfortable'* (Louise; Interview 2; Lines 80-92).

Tsai and colleagues (2010) described chemotherapy associated fatigue as the most intense symptom prevalent in the majority of the fifteen participants as well as the vicious circle, as depicted in the above quotation from Susan's second interview, encompassing nausea, vomiting, poor sleep and lack of appetite. A number of factors have been identified as of importance in affecting the likelihood of post-chemotherapy nausea including chemotherapy regime (e.g.

Hesketh, 2008) and experiencing nausea during pregnancy (e.g. Grunberg, 2004) though it should be noted that neither study was focused on women with breast cancer. As previously noted in this theme participants anticipated chemotherapy-induced nausea and positive associations between expectations and nausea have been reported via a meta-analysis incorporating numerous studies with a breast cancer population (Colagiuri & Zachariae, 2010). A psychological role in the physical experience of nausea was acknowledged by several participants however the following quotation depicts a unique aspect of this relationship.

*'Before the last session of intravenous chemotherapy obviously it's all psychological. a couple of days before I was going, I have the cold cap. and I found a tissue in my pocket and it's a tissue they use to put on your temples and when I took the cap off I must have put it in my pocket and when I put my jeans on this tissue was in my pocket and as soon as I saw it, it made me wanna be sick' (Mary; Interview 2; Lines 53-58).*

Consequently sensory association was found to play a role in Mary's experience of chemotherapy though a number of physical changes to the body were more commonly reported.

*'There's eight days where I'm really sick and then the rest of the time just feeling it, tired. It changes your whole body really. it must be the sickness tablets, they give you steroids as well. That just changes the shape of your body and your tastes. I get that metal taste all the time. My taste in foods changed. I like salt and pepper now and anything*

*spicy and I think it's just to cut through that taste'* (Janet; Interview 2; Lines 16-21).

Similarly, Mary commented:

*'Other than the sickness it's just feeling very lethargic and the horrible feeling in your mouth that you get, you really don't fancy any food and even when you do have food it doesn't taste right. Well, it's more the feeling anyway. I just feel like my mouth is covered in wax and the more you brush your teeth to make it go away you make your mouth sore'* (Mary; Interview 1; Lines 389-394).

Unlike other side-effects these women had not anticipated gustatory changes however, this led several participants to begin a process of experimentation with foods to cope with this symptom. Experimental research has revealed that chemotherapy significantly decreases the olfactory and gustatory function of women diagnosed with breast cancer (Steinbach et al., 2009). Although found to be a transient effect with salty tastes being most affected and gustatory function significantly influenced by chemotherapeutic agent, the changes had an impact on women's chemotherapy associated morbidity and quality of life. The effects of chemotherapy are further discussed in the following sub-theme with consideration of relevant participants' experiences of hair loss.

### **6.5.2 Chemotherapy-induced alopecia**

Developing an illness identity, one which participants associated (given their cancer schemas) with cancer, often stemmed from hair loss as opposed to having undergone breast surgery. This was evident during the first interviews as even prior to the commencement of chemotherapy some participants began to

engage active anticipatory coping strategies to minimise the potential stress of undergoing chemotherapy and to take control of hair loss.

*'I know it's not gonna be nice and I'm more bothered about being sick. I hate being sick, I can't cope with it. I know there's gonna be a good chance my hair will fall out, of losing that, so I've had it chopped off quite a lot. I thought it's not such a drastic thing if I do it in stages. She says I might not and I can have a cold cap or something but we'll see. I always take things as they come'* (Janet; Interview 1; Lines 114-119).

This finding provides support for a UK based qualitative study that aimed to overcome some of the criticisms of the existing literature available on chemotherapy-induced alopecia. Focusing on hair loss in breast cancer patients Frith, Harcourt and Fussell (2007) reported interview data from nineteen women collected either immediately prior to or at the beginning of chemotherapy and again at the end of treatment. They too found that women anticipated hair loss but reported this to be the most feared symptom which contradicts the views of the women in the current research study who perceived sickness to be the worst possible outcome. Managing hair loss before its occurrence as depicted in Janet's previous quotation was also identified by Frith and colleagues which they noted to be acceptance of the inevitability of hair loss. However, as is to be shown later in this chapter women often retained hope that they would not lose all of their hair and took measures to minimise such loss from the first treatment rather than equip themselves with a range of attire to disguise chemotherapy-induced alopecia prior to its commencement.

Hair is historically viewed as a symbol of social, cultural, religious and political status and is associated with age, gender, and beauty (Hansen, 2007). The

importance of hair loss can be illustrated through several studies which have shown that the fear of hair loss can lead to a refusal to undergo chemotherapy (e.g. Batchelor, 2001). Previous research has shown that for some women coping with hair loss is more difficult than losing a breast (Freedman, 1994). The following quotation from Susan suggests that for her it was the combination of a bilateral mastectomy and hair loss that caused the greatest period of suffering in relation to the changed body.

*'I think if I'd had both breasts removed right at the beginning erm.in those days I had reasonably long hair, shoulder length hair, I think I would have felt that all of my feminine attributes hadn't gone because I still had my hair'* (Susan; Interview 2; Lines 125-128).

The findings of the present study support those documented in a literature review of thirty eight studies examining chemotherapy-induced alopecia (Lemieux, Maunsell & Provencher, 2008). Hair loss was reported to be amongst the most troublesome side-effects being consistently ranked in the top three by women with breast cancer. The review further concluded hair loss to be traumatising and distressing for women though highlighted the lack of studies considering its importance and the psychological impact for women with breast cancer. For women in the current research study hair loss was described as an outward sign of illness, a visual representation of cancer, and was associated with being stigmatised by others.

*'It sounds really vain and I'm not vain at all but I think when you lose your hair you look like you've got cancer don't you'* (Laura; Interview 2; Lines 81-82).

Likewise Emma commented:

*'I think the way people are they just glare and that don't they. I mean if I see someone with hair like this, even before this happened to me and I wouldn't think oh look at her she's got no hair. I would look at someone like this and think she's on some sort of treatment'* (Emma; Interview 1; Lines 93-96).

Using Goffman's notion of stigma as a conceptual analytic framework Rosman (2004) applied grounded theory to interviews with thirty five individuals at least one year post diagnosis with breast or lung cancer. She subsequently described how, as illustrated through Emma's quotation, hair loss can lead to a direct confrontation with the seriousness of breast cancer. Rosman (2004) argues that patients with chemotherapy-induced alopecia are discredited given when hair loss is not hidden, their stigma is instantly visible and as such increases an individual's identity as a cancer patient. Women's accounts of their hair loss illustrate such concerns and the potential impact on the self when the individual is not recognised as the same person by others.

*'I think it just attracts attention to what's happening to me. Perhaps that people I meet might think this is a cancer sufferer not a person'* (Joan; Interview 1; Lines 162-163).

Rosman (2004) additionally contends that the stigma associated with being labelled a cancer patient can lead to an individual being vulnerable to negative self identification and self definition. The following quotation from Rose demonstrates how women's beliefs about the perceptions of others regarding their hair loss can be at odds with their own feelings regarding their health.

*'The hair loss has been horrible, that's been the worst part. I've tried to keep my hair by wearing the cold caps but it's gone very thin. I think*

*really it's what people see isn't it. People see you without hair and they look.and know.I don't want people to think.I don't feel ill'* (Rose; Interview 1; Lines 119-123).

In support of previous research findings, several women in the sample including Emma explicitly linked hair loss with a loss of feminine identity and experiencing a life threatening illness.

*'My hairs completely fallen out and I'm devastated. I have to wear my wig when I go out because I don't want anyone to see me without any hair... you don't look like a woman do you and you look like you're dying'* (Emma; Interview 2; Lines 10-12...16).

In relation to breast cancer chemotherapy-induced hair loss has been found to denote a loss of individuality, attractiveness, and sexuality (Freedman, 1994) as well as a lack of vitality, strength and health (Rosman, 2004). Similarly, through ethnographic fieldwork comprising participant observation of women undertaking cancer rehabilitation courses in Denmark Hansen (2007) reported baldness as being associated with gender, death and a loss of womanhood, the latter being influenced by women's perceived loss of femininity, sexuality, self-confidence and attractiveness. Facial hair loss further changed women's appearance thereby confirming their illness status.

*'I lost my eyelashes and eyebrows.that was the worst thing.your eyebrows define your face'* (Susan; Interview 1; Lines 222-223).

The loss of eyelashes was identified by Sarah as particularly problematic resulting in discomfort.



*'I lost a lot of my eyelashes, which has caused me quite a lot of problems because I've had more irritation in my eyes and more erm.well inflammation of the eyelids I've had actually. I've had more infections where the drips have gone, less tolerant I think to my body'* (Sarah; Interview 2; Lines 30-34).

Sarah was the only woman in the sample experiencing a recurrence and the above quotation provides some insight into her view of her body's decreased ability to cope with chemotherapy for a second time and depicts her disembodied status. In contrast to a secondary analysis of interview data gathered from UK participants with chemotherapy-induced alopecia (Hilton, Hunt, Emslie, Salinas & Ziebland, 2008) the women in the present study spoke not only of hair loss above the eye line but of alopecia from wider bodily surfaces.

*'It's still coming out with every treatment and I've lost it from my armpits, legs and everywhere else you have hair'* (Janet; Interview 2; Lines 62-64).

The study by Hilton and colleagues found such discussions to be limited to male cancer patients however women in the current research relished relaying events such as once again having to shave as for them this was another representation of normality.

*'A very exciting thing was when I had to shave my legs (laughing) and I thought what a sad person getting excited about shaving your legs but it is, it's a sign of normality coming back'* (Susan; Interview 2; Lines 385-387).

By the third interview, when chemotherapy had been completed, participants made efforts to discuss positive outcomes.

*'I've always had straight hair and its come back curly...I lost most of my hair but it's come back curly, I've always wanted curly hair and I've got it'*  
(Janet; Interview 3; Lines 39-40).

While the completion of chemotherapy and hair re-growth was perceived to be a sign of health returning, women subsequently attended radiotherapy which, as illustrated in the following sub-theme, had an unexpected impact on the body.

### **6.5.3 Radiotherapy: an unanticipated impact on the body**

Contrary to previous qualitative research findings (Halkett, Kristjanson & Lobb, 2008) the thirteen women in the present study prescribed radiotherapy did not report what could be considered fears about this treatment and did not actively seek information about radiotherapy. For the ten women who had previously undergone chemotherapy this intervention was perceived to be less problematic in terms of side-effects and displaying the signs of illness.

*'I feel a bit.I feel a bit.I think.gutted because I feel so okay and I think I feel really well and I'm still having to go through this but.I don't feel half as worked up as I did about the chemotherapy and I think it's because there's not as many side effects'* (Laura; Interview 2; Lines 25-28).

As illustrated by Laura radiotherapy was perceived to extend women's wait for normality however while participants did not anticipate experiencing side-effects the majority of women interviewed did describe skin irritation. This was the case both for participants who did and did not undergo a course of chemotherapy.

*'I realised I had no sensation in this area here (points to part of chest and lower arm) so when you can't feel anything it doesn't hurt does it. I started to peel in the area that had the radiotherapy, it was like having bad sunburn, and it itched like mad all around the edges where I did have sensation' (Lily; Interview 2; Lines 17-21).*

Joan additionally commented on the visible nature of this treatment effect.

*'You can probably see on my neck there because the clavicle was done. I keep plastering sun block on that but it's a lot better than it was. It was an open wound at one time' (Joan; Interview 2; Lines 59-61).*

Attending hospital each day for an allocated time period was also viewed as contributing to physical limitations by adding to a generalised fatigue.

*'With the radiotherapy, going down every day doesn't give you enough time to stand back and think. To lie on a table with your legs on this thing so you can't move and your head in a thing and an enormous machine above you, is quite intimidating. You can hear the machine warming up and then discharging.it felt like I was in a Sci-Fi movie...entering my body and burning away these cells. I don't think I ever came to terms with it.and I had five weeks of it.it was odd. If I had to do it again I don't think it would be as bad. It does make you tired, just going to hospital every day.finding somewhere to park.is quite strenuous' (Susan; Interview 1; Lines 187-196).*

Susan's quotation provides an insight into how the continuous adherence to medical regimes throughout the healthcare trajectory can limit women's time for reflection and how she viewed her body in relation to the process of radiotherapy. While Susan does make reference to "my body" suggesting an embodied perspective she subsequently comments on "these cells"

contradicting the notion of embodiment. Throughout this research it was not uncommon for women to speak of their bodies in a way that indicates the individual body parts and internal structures of the body were seen from a disembodied perspective yet the body as a whole was their property and to some extent under their control. Given its self-administered nature it could be argued that women had ultimate control over taking Tamoxifen yet as is considered in the forthcoming sub-theme this was also not without noticeable effects on the body.

#### **6.5.4 Tamoxifen: inducing the menopause**

For all participants with oestrogen receptor positive tumours Tamoxifen was prescribed for five years however side-effects were experienced almost immediately ranging from mild hot flushes to profuse sweating and insomnia with varying degrees of severity.

*'Since I've been taking it I'm not sleeping on the night, I've got like insomnia. It must act as a sort of diuretic because it makes you pass water quite frequently. I don't get the nausea and the headaches now. after about ten days. so that's quite a good sign. So, whether all the other things will sort out after I've been taking it a while'* (Gillian; Interview 1; Lines 114-118).

While the longitudinal approach has uncovered that these side-effects tended to improve over time, several participants continued to experience issues, some of an externally visible nature, several months after commencing the drug treatment. This prolonged these women's wait for normality and limited the extent to which a healthy identity could be resumed.

*'Tamoxifen is horrible. You don't get more than two hours sleep at a time and you wake up soaked in sweat, so you've got to change your nightie, sometimes change the sheets. So, I'm never sleeping more than two hours at a time. and then once I'm awake that's it...I guess initially when I was thinking well it doesn't matter if it prevents the cancer returning. now, now the reality of five years of this isn't very nice'* (Ellen; Interview 2; Lines 43-46...50-52).

There is a paucity of qualitative research exploring women's experiences of Tamoxifen though similar findings have been reported in a French interview study considering the adherence of thirty four women who had commenced Tamoxifen (Pellegrini et al., 2010). As in the present research study Pellegrini et al. described side-effects including hot flushes and night sweats which characterised a loss of control over the body and led to concerns regarding femininity and further deterioration of body image. These latter issues are illustrated through the following quotation from Ellen who commenced Tamoxifen within days of undergoing breast surgery.

*'I thought I was going to have nasty symptoms with it because the first week I took it I felt really sick, really awful, but they've passed. Just knowing that the oestrogen in my body is now blocked. I'm waiting to grow a beard and. (laughing) waiting for all sorts to happen, you know. Erm. and I think that's a really big stumbling block for me, knowing that outwardly I don't look like a woman should and now I'm thinking internally as well that's getting blocked'* (Ellen; Interview 1; Lines 189-195).

Severe side-effects have been identified as an influential factor in women's adherence to Tamoxifen particularly during the first year (Owusu et al., 2008). Moreover, in a self-report survey of side-effects and both physical and mental

status Tamoxifen was found to have detrimental effects on women's quality of life (Boehm et al., 2009). As demonstrated below, this study's participants accepted whatever side-effects they experienced and even when given the option of temporarily ceasing the treatment chose not to do so.

*'She did say she would take me off the Tamoxifen but that it would be a mind game for me if I did but she said it's entirely up to you but she said I'd only let you come off it for three months. So I thought about it and I thought it really isn't worth it, I'll try the glucosamine and luckily for me it has worked'* (Amanda; Interview 3; Lines 61-65).

Like Amanda, the other participants typically faced a multitude of treatments and in turn side-effects which were experienced to varying degrees. This theme has depicted the impact of these side-effects on women's body perceptions though in accordance with the previous quotation, it is noteworthy that fear of mortality outweighed experiences of such side-effects and led a small number of participants to seek out alternative therapies to cope with treatment-induced symptoms. This is one area explored further in the second part of this chapter.

## **Part 2 - Body Management**

Strategies relating to the management of the body and external appearances to minimise the impact of breast cancer on participants' lives is the focus of the second part of this chapter. Use of external breast prostheses, reconstructive surgery and long-term management of appearance via clothing choices are examined. The methods of managing chemotherapy-induced alopecia adopted by women in this study are reviewed as is the use of complementary therapies to manage the impact of treatment-induced side-effects on the body and mind.

## 6.6 The practicalities of external breast prostheses

There is a paucity of empirical research focusing on post mastectomy care and specifically the provision of breast prostheses (Gallagher, Buckmaster, O'Carroll, Kiernan & Geraghty, 2010). However, the majority of women who have undergone breast cancer surgery particularly mastectomy will require use of an external breast prosthesis (e.g. Scanlon, 2004). All women in the current study who underwent mastectomy were offered a soft breast prosthesis following surgery, typically prior to discharge. In line with writers such as Lorde (1985) it could be argued that this sanctioning of prostheses is of benefit to society ensuring that public optimism regarding breast cancer is not spoiled. Moreover, Bredin (1999) argues that this reinforces the concealing of breast loss and the need to maintain "normality" of the body. Nevertheless, participants viewed the provision of prostheses in a positive manner and it was evident that the impact of the changed body was felt immediately after surgery.

*'I just kept looking at it and thought well this is how it is but then when I was coming home and they gave me the erm.the little softie, the soft prosthesis, that was just.a massive change for me because I came out and I looked normal. That's what I didn't like and I couldn't.probably it was worse for me because my breasts are quite big anyway, that it was so flat on one side and not on the other so.you've got your dressing gown on and it's so obvious when you're in hospital' (Mary; Interview 1; Lines 191-197).*

The provision of a good-quality prosthesis and prosthesis fitting service have been identified as of importance for women's post-surgical recovery including psychosocial well-being and body image (Breast Cancer Care, 2006). Sensitivity and understanding have been identified as key qualities of the

person fitting the prosthesis with women preferring a knowledgeable fitter such as a breast care nurse to conduct the primary fitting (Roberts et al., 2003). While all women in the present study required this service preparation for the fitting appointment has been reported to be useful. Acquiring a prosthesis prior to discharge limits the extent of possible preparations and for Pauline such issues are reflected in her concerns as to the introduction of the prosthesis.

*'It was almost as an afterthought that I was given a prosthetic on the morning that I was going home and it was just the presentation of it. It was a huge bag with all different sizes and it was well this one looks about right, here you are. I can cope with that but I think a lot of people would have been very distressed and would have to have been taken to one side'* (Pauline; Interview 1; Lines 238-243).

Aspects of the prosthesis fitting environment including insufficient space and poor display of stock have been repeatedly criticised by women as negatively impacting upon the fitting experience (Breast Cancer Care, 2006; Gallagher et al., 2010) though while Pauline expressed concern for others none of the other women in the sample commented on the fitting itself. As in the focus group study of Irish women's accounts of external breast prostheses (Gallagher et al., 2010) a number of practical issues pertaining to the characteristics of the external breast prostheses were raised as, for example, several women reported experiencing pain and discomfort during the post-operative period when wearing a bra.

*'I had an appointment at the clinic and they gave me a bra and it was really good, with pockets in. Now, oh get this, I've got a little old lady who sews me pockets into my bras, I bought her a bottle of wine, all these*



*pockets in my bras. So it's just like placing it inside and you feel so much better. I've got the soft one on at the minute but I've got my prosthesis as well, that's in my other one, my posh bra upstairs. For work I'm wearing a soft one at the minute because when I started wearing, when I first got the prosthesis and started wearing it, I was still quite tender but I put it on and I felt great and thought this looks great. I felt more normal than I'd ever felt but I didn't know you had to do it gradually so I wore it all the time and now I have a very slight tenderness. It doesn't even hurt to the touch, it's hard to describe, it's a funny sort of thing, but it's like when you have your socks on tight and it leaves a mark' (Jenny; Interview 1; Lines 285-299).*

Jenny's quotation provides an opportunity to mention that once surgical wounds had healed sufficiently women were offered a follow-up appointment for the fitting of a silicone prosthesis and bra containing pockets in which either type of prosthesis could be inserted. The bras were well received by participants however the silicone prostheses were deemed to be heavy and were described as inducing a sticky sensation due to sweating particularly during warm weather.

*'I wore my prosthesis on the day I got married. All the men wore kilts and they were so busy seeing to him (husband) and the bloody kilt I was struggling with the bra. My husband fastened me the bra and erm. I think I wore this falsie upside down all day. I'll be honest with you I don't like it. I don't like it because when you've got it on you've got to sit like that and with it being this hot weather when you take it off you're sweating' (Linda; Interview 1; Lines 216-222).*

Furthermore, Linda found that achieving a symmetrical bust line with an external breast prosthesis was difficult and the assistance she required in doing so resulted in feeling self-conscious.

*'I've promised to try with my falsie a bit more. Yesterday when it was so hot I just have my cotton trousers and a T-shirt on, like now...I feel more self-conscious when I've got it in but we're putting it in now, we've had two attempts at putting it in and my husband's looking to see if my bust is level and I feel more self-conscious then'* (Linda; Interview 1; Lines 279-288).

The issues experienced when wearing external prostheses seemed to be amplified for those participants who had both breasts removed though is a neglected element within existing research.

*'Having two prostheses is much hotter than when I just had one and the perspiration just pours off me. I think it's because they're plastic and are flat to the skin so there's no movement of air around them. They move in a different way to your own breasts. Breasts hang from the shoulders in a way but the prostheses hang in your bra and it's almost like getting used to foreign bodies. Putting one in I could get used to it but now I have two I'm always aware they're there. I know that sensation will go. Those are the sorts of things you don't really think about. I'm not wearing them all day'* (Susan; Interview 2; Lines 395-402).

Accordingly, in support of the findings of Gallagher and colleagues (2010), participants experienced issues associated with prosthesis weight, discomfort and the body shape that could be achieved with the prosthesis that had been supplied by the NHS. As a consequence, experimentation with different types of

prosthesis was common practice amongst the women interviewed. A need to be confident in wearing whatever prosthesis was chosen was also evident.

*'I wear quite firm ones for work but they're very hot. I've got hollowed out ones to exercise in and they're great, I just daren't wear them for work in case they collapse. I think I need to wear them around the house a bit more to get more confidence with them. They are much, much better when you're exercising because they don't pull the sweat back onto your skin and don't pull your scars so they're much, much nicer so I've bought myself a set' (Ellen; Interview 3; Lines 360-366).*

As reported elsewhere (e.g. Gallagher et al., 2010) the perceived need to find appropriate prostheses and clothing to suit was described as having financial implications.

*'I'm not a fashion victim but I do like to wear stylish things and I find it quite restrictive. You get away with a lot with camisoles but it's the underwear issue that's the problem and because I'm small chested anyway I get a ridge here. I've got a couple of softies now and I've bought an extra one and what I did was get some filling, about a centimetre across the top and that's helped but it's still not. with ordinary foam, the nature of the foam, it's so fragile, they can't cut it to a wafer thin edge like they can with the latex but I didn't like it at all. I even bought a stick on one thinking that would be better. and the prices are horrendous. I feel as though I've been punished almost, penalised because I've had breast cancer and a mastectomy so I have to pay one hundred pounds for a prosthetic and another sixty pounds for the*

*adhesive and they don't last very long'* (Pauline; Interview 2; Lines 37-49).

Pauline's quotation makes reference to having small breasts though seemingly in contrast to the research of Fang et al. (2011) this did not minimise the impact of mastectomy but actually elicited issues regarding finding an appropriate prosthesis. Moreover, while participants had received a "pocketed" bra from the breast clinic any adjustments to existing or newly acquired bras were the responsibility of the individual woman, often incurring a financial cost. The subsequent theme explores the difficulties participants experienced with external breast prostheses and illustrates how their desire to restore their body to as full an extent as possible occasionally led women to consider and in some cases undergo breast reconstructive surgery within the year following diagnosis.

## **6.7 Reconstructive surgery**

Women's consideration of reconstructive surgery was complex and by the end of the data collection period information seeking about this procedure did not necessarily extend to scheduling surgery. Susan, for example, reported severe soreness following a bilateral mastectomy and by her final interview was contemplating all options despite previously being against reconstruction.

*'Everyone knows I've been against it and I said I wasn't getting away with the prostheses...I know a few people who've had it and they're not always as successful as people like to think and so I'm debating. I doubt I'm properly healed inside yet either so it might just be pressing on a bit that's still healing for all I know but I suppose it needs looking at and sorting out. I just think you get all these scars all over your body and a false breast doesn't really look like a breast when you take your bra off*

*does it, you look like a Barbie doll'* (Susan; Interview 3; Lines 113-114...117-123).

Interestingly, the experiences of others and specifically concerns about the success of the surgery in terms of altered appearance formed Susan's rationalisation against breast reconstruction. This may link with the study findings reported in Chapter 1 (p.27) noting that breast reconstruction does not meet all women's expectations (e.g. Cromptoets, 2006) and moreover, that being aware of this may influence some women's decision to decline this procedure. However, despite experiencing few issues with external breast prostheses a minority of women in the sample did not perceive adjustment to their changed body to be possible and actively sought a breast reconstruction during the year following diagnosis. At a very early point in her first interview Gillian made reference to how losing her breast was of greater significance than having cancer. This is not only in contrast to previous literature (e.g. Fallowfield & Hall, 1991) but to other women interviewed as part of the present study as detailed in the previous chapter.

*'I was absolutely devastated about the mastectomy. At that time I don't think breast cancer even entered my head really, it was just the fact that I was losing my breast and I didn't want to. It wasn't the fact that I had cancer, that didn't come into it at the time'* (Gillian; Interview 1; Lines 40-43).

Medical reasons meant that immediate reconstructive surgery was not possible for Gillian and accordingly even at this early stage her primary focus became this intervention.

*'I think I've been asking for that ever since they first told me. I think I ask every time I see her. She'll get sick of me but hopefully I'll then be at the top of the list'* (Gillian; Interview 1; Lines 71 -73).

Lorde (1985) purports that reconstruction and the use of external breast prostheses undermines women's attempts to reassert control over their lives. Yet for Gillian the process of seeking this surgery seemed to engender control over her future body-self. Not surprisingly, her wait for breast reconstruction was the first topic Gillian raised during her second interview which subsequently revolved around this discussion point as Gillian did not perceive being able to regain her former life without the surgery.

*'I just want my life back really and I will but not until I've had that. I'm quite a.I've got quite a good social life and I like to go on holiday and I just wouldn't feel comfortable. I don't know even the clothes I like.you cannot even wear little like vests, particularly when you're leaning forward.you know.it's not.I'm not comfortable. So yeah.for me.I just feel it's like the next step in my recovery really.for that'* (Gillian; Interview 2; Lines 47-52).

As described elsewhere (van Wersch, 2001) clothing was an influential factor in Gillian's quest for breast reconstruction as she continued to feel self-conscious. By the third and final interview Gillian had undergone breast reconstructive surgery and the following quotation illustrates the impact on her body image and well-being.

*'When I look in the mirror now I don't.like before I used to be upset and that but now.although I've got scars and everything at least you've got something there'* (Gillian; Interview 3; Lines 27-29).

Higher levels of satisfaction with appearance both with and without clothing and greater confidence in social situations have been reported in women who have undergone delayed breast reconstruction compared to women with unilateral mastectomy (The NHS Information Centre, 2011).

Gillian's difficulties accepting breast loss were the most prominent in the sample and the longitudinal qualitative approach was particularly valuable in revealing her experience of seeking and undergoing reconstruction. Elements of her first and second interviews conform to Frank's (1995) conceptualisation of a chaos narrative whereby the story is one of wreckage and the individual cannot imagine life improving. Her continual pursuit of reconstruction, however, indicates the presence of a restitution narrative and consequently Gillian's case provides an example of how women may display multiple narrative types often simultaneously during their experience. It additionally provides evidence that a minority of women may reject living with breast loss from the point of diagnosis. In accordance with van Wersch (2001) reinstating her outer self may have minimised the change required to Gillian's inner self in the long-term.

While quantitative research has shown that women perceive one of the major benefits of immediate breast reconstruction to be avoiding the need for external prosthesis use (Contant et al., 2004) this was not described as an influential factor by Gillian, rather breast loss itself underpinned her drive to have reconstructive surgery. Her use of an external breast prosthesis was viewed as simply serving a temporary purpose though was not deemed as alleviating her suffering sufficiently to warrant long-term use. It is noteworthy that even those participants who emphasised survival over breast loss and did not perceive the changed body to impact their sense of self chose to wear an external breast

prosthesis when in social encounters and/or altered their dressing behaviour in some way. This thereby supports Crouch and McKenzie's (2000) observation that it is unusual for women to forego either the use of a prosthesis or breast reconstruction. It should not be forgotten that many participants did just this when in a "safe" environment such as at home with loved ones or when breast loss could be adequately disguised through careful consideration of clothing. Yet it is this daily change to these women's lives that indicates, as in the previous chapter, that in relation to Frank's (1995) restitution narrative that full restoration is not possible given the consciousness required to maintain "normality".

With regard to those women who had undergone a lumpectomy the commentary in this theme is not intended to imply that, as empirical research shows, (e.g. Fobair et al., 2006; Moreira & Canavarro, 2010) participants with mastectomy did not experience greater altered body image than those having undergone breast conserving surgery. Rather the themes of this chapter illustrate the profound impact of breast loss however, the qualitative approach adopted in the present study has helped to identify that irrespective of the type of breast surgery women had undergone, an altered sense of body-self and associated social identity may be experienced. Discussion of women's management of their external appearance is expanded in the next theme wherein participants dressing behaviour is reviewed in relation to both mastectomy and breast-conserving surgery.



## 6.8 Re-imaging the body to manage breast surgery

Despite the daily difficulties participants faced wearing external breast prostheses the positive psychosocial impact attained by restoring their body shape and appearing "normal" was, as found by Roberts and colleagues (2003), central in women's accounts of their experience following breast surgery.

*'When I have a prosthesis in nobody knows any different when I'm out. I haven't had any problems. I can get back to doing what I did before. Nobody will have any idea that I have lost my breast. I think the days of thinking about being a page three model went a long time ago. I would rather lose the whole breast and get rid of the cancer' (Susan; Interview 1; Lines 141-147).*

The previous quotation from Susan reiterates the viewpoint of several women that losing a breast is a small price to pay compared to losing one's life. Furthermore, while the wearing of a prosthesis did not typically restrict activities of daily living, adjustment to breast surgery and an external prosthesis required participants to re-consider their dressing behaviour.

*'I phoned the breast care nurse actually because we're going out on the 25<sup>th</sup>, which is before I get my prosthesis because I've only got the softie at the moment erm.and so I phoned and said could I go in earlier because I would like it for when we go out. She said yeah, not a problem but why and I said well I just have this feeling that when I go in everyone's gonna stop, turn around and stare at me. I know they're not but I have this vision in my head like everyone's gonna go quiet and look at me, although nobody will know apart from my close friends. Nobody will know but you just have this perception of people staring at you, or if they look at you, that's why they're looking at you.not because you look*

*nice or anything like that. I think I'll probably still wear the softie one because it's pretty comfortable really and it doesn't weigh anything whereas I think the actual prostheses are quite heavy so I'll probably only wear that if I was going out'* (Gillian; Interview 1; Lines 320-335).

The fear of being stared at, formerly recorded by Rasmussen and colleagues (2010), and having others speculate about their breast surgery was a common reaction during the first months. Indeed, the influence of others permeated women's accounts of this element of their experience. As in the present study Thomas-MacLean (2005) reported that women attempt to restore the body and in doing so avoid stigmatisation from others via managing their appearance. The following quotation from Margaret, who underwent a lumpectomy, illustrates how feeling self-conscious resulted in her disguising her breast surgery.

*'I must say when I first went away (on holiday) I thought oh sod it if they don't like it they don't have to look and I did and then I thought no I can't. I just couldn't do it I had to put my top back on. So...I feel as though...I'm self-conscious and I'd think well people would be looking at you and thinking what's she had done...so I feel as though that part's been taken away from me so you do feel a little bit...unhappy'* (Margaret; Interview 1; Lines 197-206).

Manderson and Stirling (2007) reported that women frequently feel self-consciousness post mastectomy yet the current research findings highlight this too is the case for women following breast-conserving surgery. Women's concealment of the body, withdrawal and changed behaviour when around others following breast surgery is argued to represent women's altered social

identity (e.g. Bredin, 1999; Spence, 2001). The extract below taken from the second interview with Rose exemplifies the complex interplay of factors and decision-making processes involved in dressing the body and the wearing of external breast prostheses following mastectomy.

*I've got quite a few camisoles in various colours that I can wear underneath anything, anything that's slightly revealing and I find that at the moment I can't wear. I'm going to have to order a new contact.prosthesis bra. At the moment I haven't got one so when you bend over, if something's a bit sort of.(low cut), it's going to go over like that, your bra comes away, the weight of it pulls your bra away. Obviously that's not a very nice sight so hopefully once I get a contact bra I'll be able to wear something that's not as tight around my chest, so when I do bend over you just see my bra basically. It's amazing how many clothes are low necked and it doesn't matter you know, it could be here, but you could still see because it's deep here. It doesn't really bother me that much but I would hate to upset somebody else, you know, for what they could see, if you know what I mean. So, hopefully I'll get this new filler and see how that works because once you get your clothes on you're just like everybody else. It's the preparing in your head, what am I gonna put on and also with the scarves as well, what have I got.can I wear that top, have I got something that's gonna go with that. So, it's a bit more complicated to get ready and you've got to think about your clothes more rather than going in the wardrobe and thinking oh I'll put that on' (Rose; Interview 2; Lines 93-110).*

Disguising breast loss was therefore viewed as a means of protecting others and led to careful consideration each day as to the appropriate clothing given

potential social interactions. The following quotation from a highly emotional section of Gillian's first interview reveals the moment she began to perceive necessary changes in dressing her body.

*'A couple of weeks ago my daughter bought some clothes and it was the sort of things I would have worn before my operation so it sort of brought it home to me that I won't be doing that sort of thing for a while. I wouldn't feel comfortable wearing clothes that I wore before, not like everyday clothes but clothes you wear when you're going out socialising. All the clothes are low cut because that's the fashion and I just wouldn't feel comfortable any more wearing that sort of thing, not at the moment anyway'* (Gillian; Interview 1; Lines 161-170).

Feeling comfortable in one's clothes was identified to be of importance however for some participants the notion of being comfortable represented a move away from a former focus on their external appearance and ultimately their identity.

*'Yeah, it's my appearance and even my clothes don't fit me now. Now instead of dressing to look nice, I'm dressing to feel comfortable'* (Janet; Interview 2; Lines 201-202).

The existing literature on the impact of breast surgery focuses on mastectomy noting women's dissatisfaction with their appearance without clothes (Alicikus et al., 2009). In a recent audit of women eighteen months post breast cancer diagnosis 83% reported to be satisfied with their clothed appearance following mastectomy while 42% were satisfied with how they looked in the mirror unclothed (The NHS Information Centre, 2011). Consequently, clothing would seem to be integral to some women's satisfaction with their appearance yet

such results also indicate that for many women breast loss will have a prevailing impact beyond the timeframe of the present study.

Not having to change clothing options has been reported to be a perceived benefit of lumpectomy (van Wersch, 2001) however, the above quotation from Janet (and also those from other women such as Margaret), depicts how participants who had a lumpectomy also experienced issues with body image and clothing. The need to feel confident in one's dress when interacting with others at work is reflected in the following quotation.

*'I've got to feel confident in what I'm wearing otherwise I can't do my job. If I'm thinking about what I'm looking like, I'm not with the client. It's very important to me that I look reasonable'* (Ellen; Interview 2; Lines 128-131).

Despite the majority of participants dressing to cover up any signs of having undergone breast surgery a small number of women were less concerned with managing their appearance.

*'It's not very often I wear it (prosthesis). If I'm honest with you. I mean it weighed two and a half kilograms didn't it, my bust so to be honest with you it's not comfy... If we go out for dinner I will put it on, if I've got a jumper on but if I'm like this I won't bother'* (Linda; Interview 2; Lines 234-236...237-239).

This corroborates the findings of Roberts and colleagues (2003) who note that some women choose not to wear their prosthesis when alone at home. Nevertheless, a minority of women in the current study chose to solely use clothing as opposed to a combination of dress and prostheses to hide their

mastectomy when outside of the home. When questioned further Linda elaborated by stating:

*'I think I've enough confidence not to bother. Sometimes I think about it but as I said I usually wear a jacket so it wouldn't show. When I've thought about other people noticing I've always thought did I ever notice, I can never say that I ever noticed anyone with one breast' (Linda; Interview 2; Lines 265-269).*

This is an interesting observation from Linda and could be argued demonstrates not only women's proficiency at disguising breast loss but the overwhelming desire to maintain a public display of a "normal" appearance. Older age was often perceived to influence the views of those participants who chose not to alter their wardrobe.

*'I don't see any reason why I won't wear vest tops. My summer clothes are there and last weekend I was wearing them no problem, it didn't bother me but it might affect a younger person, they might be self-conscious. I don't feel as if I'm not a complete woman or anything like that, not at my age' (Maria; Interview 2; Lines 153-156).*

For some participants, however, there were exceptions to not hiding breast surgery including sunbathing and swimming.

*'I think because it's been winter I've been wearing big baggy things anyway but I'll have to think more during the summer, but I'm not ashamed of having had a mastectomy. I just probably wouldn't put on any beachwear but anything else I'm sure I'll be fine' (Lily; Interview 2; Lines 149-153).*

While changing their "normal" attire was evident throughout many participants' experiences, for Ellen who some years earlier had undergone a previous

bilateral mastectomy following high risk genetic testing, buying new clothes and specifically underwear, had become a means to gain confidence, boost mood and promote a positive sense of self.

*'You go along with weeks and you're okay and then you catch yourself in the mirror when you go in the shower and you're oh I'd forgotten. Not that you ever forget but you catch that glimpse and you feel different and strange and you've got to go out and buy yourself some fancy underwear to make yourself feel okay again'* (Ellen; Interview 1; Lines 148-152).

However, the impact of further surgery to remove a cancerous lump had resulted in a dramatic change to her body image and her previous coping strategies were no longer adopted.

*'(I have) lumps and bumps so I can't get a prosthesis that sits on my chest wall. I need two different sizes because this side has a tiny amount, a tiny amount of shape, flat but a tiny amount of shape. This side actually caves in, but it caves in and has lumps at either side so the prosthesis won't sit against me so I don't feel really confident in my clothes. So, I've had to look through my clothes and I'm in the process of throwing loads out and re-arranging. When I first went through the surgery I bought all high necks, not this surgery, ten years ago, slowly got a bit more confidence and lowered them and got nicer clothes, dressed a bit better and now I feel worse than I was then'* (Ellen; Interview 2; Lines 104-113).

When reflecting on these comments in her final interview Ellen acknowledged that:

*'I was suddenly stripped of my protective way of dressing. I couldn't dress as I normally dressed, didn't want to see neighbours, didn't want to see anybody, couldn't bear my prosthesis on'* (Ellen; Interview 3; Lines 346-348).

Ellen's account suggests that some women continue to experience emotional pain in the longer term as a direct impact of breast loss (e.g. Langellier & Sullivan, 1998) though the passage of time elicits new efforts to cope. For Ellen, seeking out specialist clothing and prostheses designed for women following breast surgery was undertaken by the third interview though she noted her fortunate financial position as enabling her to acquire tailor-made items. In contrast to previous discussions within this chapter concerning women's proficiency in disguising breast loss, chemotherapy-induced alopecia was perceived to be more difficult to conceal. Women's management of hair loss constitutes the following theme.

## **6.9 Minimising the impact of hair loss**

Research has shown that unlike men women are actively encouraged by healthcare professionals to prevent and disguise hair loss (Hilton et al., 2008). Participants did indeed often attempt to minimise the likelihood of hair loss while undergoing chemotherapy by opting for scalp cooling otherwise known as scalp hypothermia. The potential benefits of using a cold cap were introduced by the oncology team however when this was not as successful at preserving hair as had been hoped women were encouraged to cease its use.

*'My hair erm.the last one.by the last one it had dropped out a lot so I asked the nurse if I should continue with the cold cap and she said no*



*because you wouldn't be able to tolerate it because there was so much dropped out. So you know, I've got over that because it was a bit of a shock my hair falling out'* (Louise; Interview 2; Lines 9-13).

Trials testing scalp hypothermia versus no use of the cold cap in a breast cancer population have not elicited statistically significant differences in women's alopecia related distress (Protiere et al., 2002 as cited in Lemieux et al., 2008). However, for women in the present study who commenced use of the cold cap, subsequent hair loss seemed to elicit a greater sense of shock. Once hair had started to thin as in the study by Rosman (2004) not all women could bear the process of scalp cooling and preferred to lose their hair than continue with this regime.

*'I was wearing the cold caps at first, I wore them for the first three months and I found that it was starting to drop out and go very thin and it was just making me feel physically sick. It just seemed to have this smell to it, it hasn't but it just seemed to have this cold smell to it. So I thought well this is ridiculous, putting myself through something I don't have to so I decided not to wear the cold cap and I lost most of my hair'* (Rose; Interview 2; Lines 10-15).

When hair loss was becoming increasingly noticeable it was not uncommon for the study participants to take measures to reduce the distress this caused. Having hair cut short and shaving off the remainder of their hair constituted such coping strategies.

*'Well if I had to give any advice to anyone going through this as soon as you start losing your hair have it cut off. I had quite long hair and then I had it bobbed. Just before I started the radiotherapy it started coming*

*out so I'd wear my hats and erm...having to change the sheets each day, losing hair and being self-conscious of it. It started round the edges, I was losing a little bit around the edges and so you couldn't really tell but constantly every day checking yourself for hair. So one day we took the shears, myself, my partner and my friend and we just did it. I thought that would be a big step but it wasn't, it was a relief to have it all cut off* (Janet; Interview 2; Lines 41-49).

While for some of the women interviewed alopecia was viewed as an inevitable consequence of chemotherapy all relevant participants chose to disguise their hair loss to some extent through the use of hats, scarves and wigs. The choice of headwear was influenced by the weather, confidence in wearing the item and potential social interactions. This is broadly supportive of Rosman's (2004) sociological study which contextualises findings in relation to Goffman's notions of full and partial camouflage. These terms represent how individuals do not hide alopecia in the company of "initiates" such as close family yet disguise hair loss when in the presence of "non-initiates" with whom they do not wish to share their visible stigma. This is illustrated in the following quotation which also exhibits the importance these women assigned to hair loss in comparison with mastectomy.

*'This has now come second place (mastectomy) and my hair is my focus, my hair loss. Although you see you've come into my home and I don't even know you and I've let you see me like this and yet there's members of the family I won't let see me like this. I wouldn't dare answer the door with my hair like this but only because I knew you were coming'* (Mary; Interview 1; Lines 248-253).

However, having support from family and a community which held an awareness of their recent diagnosis seemed to lessen the impact of hair loss and enabled participants to choose methods of disguising baldness on the basis of comfort as opposed to normalising appearance. This finding may also link to the befriending pattern of the "tend-and-befriend" model (Taylor et al., 2000) as the maintenance of social networks reduced these women's stress response.

*'I think because I've had good support from my family, my partner and my girls so it hasn't been as bad. We do it together and I think with living in a small community I think everybody knows my condition and the girls down at work know so when I go in with my head scarf on it's not a big issue. I was supplied with a wig but I hated it. It was uncomfortable'* (Janet; Interview 2; Lines 62-68).

Rose chose to wear head scarves citing similar reasons to Janet though highlighted that for some social occasions the wearing of a wig seemed somehow appropriate.

*'I went along there (holistic centre) and they were absolutely marvellous and a wonderful range of coloured scarves, one fifty each and they show you how to tie them. I think without them I would have been stuck because I got a wig and I've worn the wig twice and I'm going to a ball at the end of this month so I may wear it again then. I've found that most people I know, most people, living in a small place, they know what my problem is so they know I have no hair. So obviously when I put a wig on they'll say oh it's a wig whereas if they didn't know me they wouldn't know it was a wig so I haven't worn my wig much at all. The scarves*

*have been marvellous and just a little thing like that'* (Rose; Interview 2; Lines 41-50).

In accordance with Rosman's findings Rose's account shows her fear that the wearing of a wig may itself become a symbol of stigma. Rosman (2004) documented that while not wearing a wig can lead the individual to be discredited due to stigma, when wearing a wig an individual may become discreditable and afflicted with an invisible stigma that influences social communication and leads the woman to consider the disclosure of their secret. Wearing a wig can thereby lead the person to move from discreditable to discredited. Feeling self-conscious when wearing a wig was rarely reported though for Janet concerns relating to failing to adequately hide her hair loss led to her largely choosing not to do so.

*'I was invited for my Christmas meal with the girls from work so I thought oh well I'll put my wig on and it did look nice and if people didn't know, they wouldn't have known but I was so self-conscious. I always thought it wasn't on straight (laughing). I'm quite happy to wear my hats and my scarves'* (Janet; Interview 2; Lines 72-76).

Nonetheless, the wearing of wigs was commonplace as like the external breast prosthesis it was associated with looking normal and effectively disguising the signs of illness.

*'I decided not to have the cold cap. I got a wig and treated it as another item of clothing. When I was out in public nobody knew...but I had to stop wearing it in the hot weather as it makes your head sore. I did think they've taken my breast and now they're gonna take my hair. It came out very quickly but the worst stage was the in between stage when I had too*

*much hair to wear the wig but not enough. I didn't want it to be obvious that I was having chemotherapy. Once I got the wig I felt loads better. I felt I could walk out and nobody would think twice. The thing that's always been important to me is being able to walk out in places where people don't know me and for people not to give me a second look. I want to try to look as normal as possible. cancer doesn't give you two heads'* (Susan; Interview 1; Lines 220-231).

Susan's quotation demonstrates the issues associated with wearing a wig and the importance of normalising appearances to avoid the stigma of cancer. This conclusion was additionally reached by Hansen (2007) who argued that the use of wigs and make-up to suppress iconic cultural references to hair loss and attempt to regain womanhood is a means of regulating the body. Louise explicitly referred to the influence of managing her appearance on her sense of self.

*'Once I put the wig on. it seems to take a long time but it probably isn't, combing it and everything. It feels really at first as if you're wearing a hat but once you forget about that, it just feels like normal hair. When I put that on I feel as though I'm back to my normal self'* (Louise; Interview 2; Lines 213-216).

Wigs were seen to engender confidence in continuing with everyday activities as illustrated in the following quotations.

*'I've got a great wig and I think that's helped me such a lot. Erm. some of my friends have even said well I like your hair in that style and I've had to say to them well it's a wig you know, so I've had a lot of confidence in wearing the wig'* (Joan; Interview 1; Lines 133-136).

Joan additionally provides support for the notion of disclosing information regarding hair loss yet this was only undertaken when women felt confident in wearing their wig. Moreover, Louise's forthcoming comment represents several women for whom location, most notably being inside the home, was the sole place they felt comfortable enough to minimise dressing the head.

*'The wig.. everyone says I look better than with my own hair (laughing), I look younger.so I'm not frightened of going out and then when I'm in the house I can wear my scarf and I'm comfortable'* (Louise; Interview 2; Lines 22-25).

Mary, who in terms of the women interviewed for this study, reported a unique experience in that a negative association was made between her newly acquired wig and undergoing chemotherapy.

*'When I went to the wig clinic I was very anxious about going but again I had a lovely experience, the lady was lovely and I come out laughing and I felt brilliant. I came home and I put this wig on and I went to see my son and I had the box and I sat in his house for an hour and he didn't know I was wearing this wig. He said to me "is that the wig in the box?" and I said "no, it's on my head" and he didn't even know, so that gave me a real boost. It is a fantastic wig but the day I went for my first chemo and like I say I felt so frightened and I was feeling sick and I was anxious and I met a lady and her mother-in-law and they were lovely, the pair of them, and that lady had a very similar wig on to mine and all I can do is relate that wig to that day. I've never took it out the box since and I hope I never have to because all I can relate it to is the day that made me feel so sick'* (Mary; Interview 1; Lines 270-282).

As a result of this experience Mary purchased both hats and scarves however she perceived wearing scarves on the head as an external indicator of illness which left her vulnerable to being stigmatised and labelled a cancer patient.

*'Hats, yes. I went to the erm.I've forgotten what they call it now.the Head Strong clinic and they showed me how to tie the scarves and I bought some scarves. I haven't even worn them because that makes it look obvious. They're still in the bag as well, next to the wig' (Mary; Interview 1; Lines 288-291).*

As undertaken by Hansen the experiences of women discussed in this theme can be applied to Foucault's (1988) technologies of the self and technologies of power. The former concept refers to the coping strategies adopted by individual women with the goal of changing or transforming herself while the associated term 'technologies of power' can be considered to be mechanisms and initiatives incorporated at organisational level with the aim of targeting individuals and regulating the body, such as the NHS provision of free wigs. While Hansen's research is specific to hair loss the themes of this chapter demonstrate that the process of regulating bodies is also undertaken in relation to breast surgery and accordingly the conceptualisation of Foucault's technologies of the self can be applied more broadly to women's experiences of the changed body. Again, as in Hansen's study women here were not found to be passive recipients of technologies of power, whether for breast prosthesis or wig provision, but rather developed a range of coping strategies for different aspects of bodily changes. Moreover, these women manipulated the forms of power designed to regulate the body to suit their personal preferences in the longer term. The knowledge that hair loss was a temporary issue helped the study participants to cope with this element of their experience.

*'It was a bit of a shock at first but you get used to it and you know it is going to grow again, you know when the treatment finishes'* (Louise; Interview 2; Lines 21-22).

As has been demonstrated in the first part of this chapter the participants experienced a variety of treatment-induced side-effects from chemotherapy and other non-surgical interventions. The following theme reports the use of complementary therapies to manage the physical and emotional side-effects of breast cancer treatment.

#### **6.10 Complementary medicine and bodily symptom management**

Access to the holistic centre offering a range of therapies including acupuncture, Reiki, reflexology, and herbal remedies, was offered to all women attending the oncology unit. The oncologist recommended the centre to a small number of women in this sample to aid the management of treatment side-effects. Women who did take up this option frequently did so for the remainder of the data collection period, beyond adjuvant treatment completion. Amanda's rationale for seeking holistic therapies was to avoid taking additional drug treatments.

*'I would prefer mind over matter than pumping a system that was already overloaded with drugs'* (Amanda; Interview 1; Lines 344-348).

Complementary therapies were used by these women not only for direct symptom management but also for psychological support following treatment side-effects.

*'I've been going to the holistic centre and I had Reiki and I found that was marvellous. I mean I wasn't sleeping very well and after the treatment I*



*had a good night's sleep and each time I was going as soon as I got home I felt relaxed and my sleep pattern has got back to normal. I've also been going for the Bach's treatment, you know, the droplets and I'm still going for that because that's for sort of confidence building and anxiety' (Louise; Interview 3; Lines 6-12).*

A recent best evidence synthesis examining the effectiveness of biofield therapies including Reiki and therapeutic touch identified only eight such studies in relation to cancer (Jain & Mills, 2010). The authors report moderate evidence for positive effects on acute cancer pain and conflicting evidence for longer-term pain, physiological indicators of relaxation, cancer-related fatigue and quality of life. However, the studies were heterogeneous in terms of types of cancer, therapy used and outcome measures under investigation. A paucity of research examining the effectiveness of alternative and complementary therapies in supporting the physical and psychological recovery of breast cancer patients is strikingly evident. Nevertheless, women in the present study spoke favourably of engaging in complementary therapies with Ellen opting for acupuncture to aid relaxation.

*'I have to admit I went in probably the most sceptical of all the people that go there (both laughing) but it's brilliant. It hurts when they go in, I do find it painful when they go in and sometimes I get a sore ear for a day or two afterwards but the relaxation something's working' (Ellen; Interview 3; Lines 299-303).*

Amanda initially tried acupuncture to aid chemotherapy-induced nausea symptoms and the following extract highlights the perceived importance she placed on this therapy in helping her to cope with this aspect of her experience.

Given this success Amanda once again sought out acupuncture when experiencing vasomotor symptoms as a result of taking Tamoxifen.

*'The first one was really, really nasty because I was sickly but on the second one I went to see the oncologist and told her that I was really sick with the first one and she recommended acupuncture at the holistic cancer care centre. If I hadn't have had that I don't think I would have coped really because every Tuesday come rain or shine I went for acupuncture and she's (holistic therapist) been absolutely fabulous. I mean it worked for me. It might not work for everyone but it did for me, fabulous and she's now helping me with the hot flushes'* (Amanda; Interview 1; Lines 121-128).

A randomised trial evaluating the effect of applied relaxation and electro-acupuncture in breast cancer treated women found both therapies to have a positive effect on vasomotor symptoms with significant reductions in hot flushes and improvements in psychological well-being (Nedstrand, Wyon, Hammar & Wijma, 2006). Despite having completed medical treatment regimes, these women's longitudinal use of complementary therapies may have served as a reminder of their breast cancer diagnosis. Participants experiences of the body acting as such as reminder is discussed in the subsequent theme.

### **Part 3 - Perceptions and management**

This final part of the chapter brings together the participants' perceptions of the body and their strategies for managing appearances by arguing that these elements of women's experience constitute a permanent reminder of breast cancer.

### 6.11 The body as a permanent reminder

Supporting empirical research evidence for this theme is somewhat limited perhaps as women's longitudinal perspectives of the impact of breast cancer are rarely the focus of attention. Nevertheless, the women interviewed for this study frequently referred to the body as a reminder of breast cancer as while they tried to disguise breast surgery inevitably when dressing/undressing and bathing the changed body became visible.

*'When I look in the mirror I..when I get up on a morning and I get dressed I forget about it all day..well most of the time..it's not until it comes to a night time when I get undressed and go in the bath or the shower and then it's sort of like..it's there again'* (Gillian; Interview 1; Lines 183-186).

Previous research has indicated that the body becomes a permanent reminder of the body's failings (Lindwall & Bergbom, 2009), the unpredictable nature of the body, fear of recurrence and death (e.g. Crouch & McKenzie, 2000). Women's accounts did not explicitly support these findings though conceivably given the cancer schemas identified (discussed in the previous chapter) and persistent concerns regarding recurrence (discussed in the following chapter) such conclusions could be drawn. However, women's explanations tended to be more positive highlighting how with time scars were fading which facilitated an increase in confidence in their body.

*'I don't feel so bad about it now..the scar is still noticeable but it is starting to go invisible. So probably by the time I go on my holidays next year I won't feel so self-conscious'* (Margaret; Interview 2; Lines 167-169).

Furthermore, in symbolising the completion of breast surgery scars were viewed as enabling a smooth transition to the next stage in the treatment plan.

*'I mean okay there will be a constant reminder there with the scar but everything has healed up fabulously so I could go on with the next step of the treatment'* (Amanda; Interview 1; Lines 287-289).

McCann and colleagues (2010) describe how physical scars meant that breast cancer had an ongoing effect on women's lives though the quotation below from Laura's second interview illustrates how for some women scars were a reminder of having had breast cancer.

*'I think it makes, well it makes me think that well that scar's there but the cancer isn't'* (Laura; Interview 2; Lines 240-241).

The following quotation from Lily does nevertheless highlight that for some women the changed body was anticipated to have a lasting effect on their lives though as reported by Roberts and colleagues (2003) integral to this was women's process of managing appearances particularly through the use of breast prostheses in the long-term.

*'Not forget it completely because I have to put this false boob in every morning, which is quite a job in itself (laughing). I'm sure it will just become a habit eventually. I am conscious that it is an ugly scar but no one else will be looking at it and I won't be wearing a bikini ever again (laughing). Nobody can see you've had anything done'* (Lily; Interview 2; Lines 82-86).

The ongoing nature of medical regimes such as Tamoxifen and having to "treat" the body on a daily basis was a further reminder of participants' experiences so far.

*'Tamoxifen's nasty.so every morning I've got to get up and swallow that Tamoxifen and have got to look at the fact that this is what's happened'* (Ellen; Interview 3; Lines 95-97).

Similarly, Pauline reported:

*'Most of the time I can forget about it and it doesn't enter my head at all but occasionally on a morning when I'm taking my pill.it's a constant reminder'* (Interview 3; Lines 62-64).

The continuing side-effects of hormonal therapy were also reported by McCann and colleagues (2010) as making it difficult for women to see an end to their experience of breast cancer. As demonstrated throughout this chapter participants experienced a heightened awareness of their body and external appearance which elicited a variety of responses and coping strategies.

## **6.12 Chapter summary**

In accordance with Frank's (1991) narrative type of the mirroring body this chapter suggests that the study participants attempted to re-create an image commensurate with an ideal "healthy" and "whole" body. This began at the point at which each individual woman perceived bodily changes to portray an unhealthy body and was exacerbated when adjuvant therapies were underway. Frank purports that with visual image being of such importance disfigurement is feared and predictability sought through normalising appearance. This is largely supported by the present research as all women engaged in problem-focused

active coping strategies (Lazarus & Folkman, 1984) to reduce the effects of breast surgery and adjuvant therapies throughout the study timeframe. However, while Frank considers the desires of this body-self to be monadic women in this study did not want to manage bodily appearances solely for themselves but for the protection of others. Moreover, the individual differences in women's acceptance of and responses to breast and hair loss evidenced throughout this chapter implies variation in the extent to which women adhere to Frank's notion of the mirroring body. As identified in the previous chapter the women interviewed typically displayed the characteristics of the disciplined body-self via medicalisation and pursuit of wellness through medical regimes. Accordingly, women may manifest differing body-self types at different stages in their illness or even simultaneously with variation arising given context, for example location (e.g. home or hospital) and social influence.

As concluded in a prior review (Al Azri et al., 2009) issues pertaining to body image were present in participants' accounts of their experience and while chemotherapy-induced alopecia was a temporary problem these women continued to manage their appearance throughout the year following diagnosis and intended to do so indefinitely. Women's process of coping with a change to their sense of self as a result of altered body image (e.g. Beatty et al., 2008) can be considered in relation to Morse's (1997) model of the development of a new self-concept (described in Chapter 2, p. 50). The primary stages of the model propose that the acute illness phase overshadows identity change. Women did indeed focus discussions in their first interviews on medical aspects of their illness and treatment yet began to experience a changed body immediately post-surgery. Morse's third stage describes how individuals are forced to recognise physical changes and begin attempts to restore functioning.

Taken in a literal sense this level of the model is perhaps not apt in the case of breast cancer as breast (or partial) loss is immediate at surgical intervention and women can do little else but recognise the occurrence of hair loss. The implication in Morse's model is for a strive for full restoration yet in relation to breast loss few women interviewed for this study took up the option of breast reconstructive surgery. That said, the study participants did attempt to restore outward appearances through external breast prostheses and for some women on a temporary basis wigs and other headwear, though this did not necessarily take place at the same point at which 'recognition' occurred.

Morse's subsequent stage termed 'striving to restore self' would seem more akin to participants' attempts to normalise appearances and again while grief and mourning for the loss of their former body was experienced this was demonstrated immediately post body change and throughout these women's experiences even when restoration was underway. Morse argues that some individuals will still strive for complete physical recovery and women frequently do so in relation to regaining normality in terms of everyday tasks (as discussed in the previous chapter) and the normalising of appearances though rarely seek more permanent solutions (breast reconstruction). The final stage of the model focuses on acceptance and learning to live with the altered self. Although the study participants did come to accept their changed body this did not mean that they did not continue to feel the impact of their altered appearance and bodily limitations due to treatment side-effects given the long-term need to manage appearances, even if for some women over time it becomes situation specific. The subsequent chapter illustrates participants' emotional journey throughout the year post diagnosis focusing on the psychological effects brought about by breast cancer and associated treatment.

## CHAPTER 7: THE MIND

### 7.1 Introduction

Participants' reflections on their experience of breast cancer illustrated an emotional journey encompassing reactions to loss as has been shown in the previous data chapters, in relation to the body, self and control over their lives. While these women's experiences were unique some commonalities in their psychological responses to breast cancer were evident with some emerging themes echoing the stages of loss represented in the models of Engel (1961) and Kubler-Ross (1969). Engel (1961) defined grief as a characteristic response to loss be it the loss of a person, job, home, body part, or treasured possession. His early conceptualisation of grief begins with the individual entering a state of shock and disbelief in which denial is a feature as the individual attempts to protect themselves from reality. The subsequent stage is marked by developing awareness of the loss during which time individuals exhibit the effects of sadness, shame, guilt, sense of loss, sleep disturbance and changed appetite as well as numerous other psychological effects. The final stage in Engel's theory is a prolonged phase of restitution and recovery wherein while mourning continues the individual experiences reinvestment in new relationships as the trauma of loss is overcome and the individual moves towards an improved state of health and well-being.

In arguably the most renowned model of the emotional processes experienced following diagnosis of a terminal illness Kubler-Ross (1969) identified five stages characteristic of grief reactions. The model proposes denial as stage one followed by anger and subsequently bargaining during which individuals may



consider strategies to bring about a longer life. Kubler-Ross argued that depression follows wherein an individual may for example ponder on the point of continuing to fight, and finally individuals develop an acceptance of their illness and upcoming death. However, unlike at the time of Engel's model conceptualisation and Kubler-Ross's (1969) publication of 'On death and dying' a diagnosis of breast cancer no longer automatically means death.

This chapter discusses participants' emotional adjustments to breast cancer and draws comparisons, where possible, with the models of Engel and Kubler-Ross. It begins with consideration of acute stress reactions which emerged at the time of diagnosis and were displayed in the immediate post-surgical period. Participants' search for meaning in relation to their illness is subsequently discussed including women's questioning of 'why me?' and facing mortality. The chapter continues by reviewing the mental distress these women experienced during the mid-point in the year following diagnosis with a focus on depression and disorientation and the most common strategies employed to facilitate coping including positive cognitive restructuring. The process of resolution incorporating participants' changed perspective and personal relationships are reported and finally the ongoing psychological impact on these women's lives is explored. Accordingly, this chapter commences with a theme depicting women's initial stress responses to receiving a diagnosis of breast cancer.

## **7.2 Acute stress reactions**

Women's experience of stress was most pronounced in their initial interviews conducted during the acute phase of their illness. Such stress reactions to diagnosis have been reported by women with breast cancer and associated

healthcare professionals (Beatty et al., 2008). Consequently these primary reactions constitute the first element in depicting participants' emotional journey. In accordance with Frank's (1995) chaos narrative women's stories at this time are of "wreckage" and highlight negative psychological reactions grounded in the present with a lack of discussion of hope for the future. Several sub-themes constitute the theme of acute stress reactions beginning with shock and disbelief.

### **7.2.1 Shock and disbelief**

Diagnosis resulted in the participants typically entering an 'alarm' stage (Selye, 1950) and anticipating a breast cancer diagnosis did not minimise the shock and disbelief experienced including by those with a history of benign breast disease.

*'That was erm.like a punch in the face, a shock. I felt quite sickly, faintly and then erm...yeah it was a big shock. You think oh my God its happened but in the back of my mind with going back and forward with cysts and things you always think this time it might not be or it could be.so yeah a big shock'* (Janet; Interview 1; Lines 19-22).

This finding supports that of Lally (2010) who following a grounded theory study of 18 women in the United States reported that shock and disbelief occurred at diagnosis despite preparedness for this news. Experiencing a lack of symptoms that women associated with cancer (cancer schema) and the short timeline from referral to diagnosis heightened the shock encountered.

*'It's such a shock isn't it. You feel so fit, go to the doctors one day and the next day they tell you you've got cancer, it's shock isn't it really more than anything'* (Elizabeth; Interview 1; Lines 142-144).

In terms of the common-sense model (Leventhal et al., 1980) women's formation of illness representations with regards to breast cancer would seem to be complicated by their limited somatic symptoms and in some cases history of breast disease as benign. Consequently, pre-existing schemas of cancer being associated with mortality combined with external information, specifically that provided by the breast care team, were of greater influence in determining the emotional representation of breast cancer and in turn coping efforts. While women were often visibly upset discussing this aspect of their experience for one woman humour was used to illustrate her reaction.

*'It's one of those moments where I don't know your eyes just, you know like the Walkers crisp adverts where the eyes just cry and you can't control yourself. It was one of those moments disbelief'* (Amanda; Interview 1; Lines 35-37).

Humour has been found to be negatively related to distress pre-surgery, post-surgery and three months after surgery (Roussi et al., 2007) and was used as a coping strategy throughout some women's experiences though Amanda was one of the few to adopt this during this early phase. Her quotation also suggests a perception of lost emotional control upon diagnosis.

Echoing the findings of Lally (2010) these women's initial emotions of shock dissipated quickly and Lally reports this to be particularly the case for older women (aged 78-87 years) and those who had previously experienced a life altering event. All of the women who participated in the present study were

younger than 70 years at the time of diagnosis however many recalled a history of stressful life events which, in addition to the limited timeframe from diagnosis to first treatment in this sample may account for this finding. Lally (2010) argues that moving on from such reactions enables women to begin to respond cognitively to their breast cancer diagnosis.

Only one woman in the sample did not describe being shocked at receiving the diagnosis. Linking with the theme of waiting discussed in chapter 5, Sarah who had undergone treatment for breast cancer ten years previously, had been expecting to have a recurrence.

*'There was no sense of shock, that was another point, it was almost as if, I almost sensed that this would happen, looking at the histories and at some stage I knew I would have a re-occurrence'* (Sarah; Interview 1; Lines 68-71).

Consequently for Sarah acceptance was instantaneous and denial did not feature in her account of her experience. The following sub-theme considers participants' experiences of denial and acceptance and highlights the complexity and inter-relationships between these notions when applied to breast cancer.

### **7.2.2 Denial versus acceptance**

Denial and acceptance are argued to have become a 'legitimate' marker in understanding responses to chronic illness (Telford, Kralik & Koch, 2006). For Kubler-Ross (1969) denial denoted the first stage in her grief model and like acceptance was viewed as a distinct stage. Engel (1961) conceptualised denial as being an integral component of shock and disbelief with acceptance

following over an extended period of time interlinked with a multitude of emotions. However, when analysing participants' accounts in relation to breast cancer denial and acceptance were found to be two extremes on the same continuum.

On denial, Kubler-Ross (1969) documented: "Denial, at least partial denial, is used by almost all patients...and functions as a buffer after unexpected or shocking news, allows the patient to collect himself, and with time, mobilize other, less radical defences" (1969; p.52). One could argue that those women who delayed help-seeking after identification of a breast symptom, as identified in chapter 5, may have been in a state of denial. However, participants' depiction of monitoring their symptoms, consciously waiting to seek help and uncertainty as to the presence of breast cancer suggests otherwise. On the surface denial did nevertheless seem to be present in the accounts of a minority of women when reflecting on receiving their diagnosis as illustrated in the below extract from Laura's first interview.

*'There was a little lady in the room opposite and I just looked at her and I thought she's picked her notes up, they're not mine. I went to the toilets and I was crying in the toilet and I thought now she's gonna tell me she's got the wrong notes.but obviously I suppose everyone thinks that, or hopes that don't they' (Laura; Interview 1; Lines 40-44).*

The use of denial pre-breast cancer surgery has been suggested to be an effective defensive strategy aiding women's coping with the stress of requiring major surgery (Jelicic, Bonke & Millar, 1993). The following quotation from Mary is also suggestive of denial at the point of diagnosis and during the initial weeks post diagnosis though illustrates the conflict in women's reactions. While Mary

exhibited denial in being unable to accept the breast cancer diagnosis she simultaneously described believing healthcare professionals, which may relate to prior discussions regarding trust in medical opinions.

*'I think.I probably just.was in shock. You're taking it in, I believed what they were saying but didn't believe what they were saying. It's funny really I still think I view this as if I'm on the outside looking in. I still don't really believe this has happened to me'* (Mary; Interview 1; Lines 35-38).

Denial may be viewed as a means of emotion-focused coping (Lazarus & Folkman, 1984) and in accordance with the theory of Folkman and colleagues (1979) this form of coping "fits" with breast cancer given its uncontrollable nature. Moreover, denial is believed to hinder acceptance of illness (Pennebaker, 1997) and is associated with general distress in women with breast cancer (e.g. Stanton et al., 2002). Nonetheless, women in the current research did not exhibit denial *per se* beyond the acute phase of their illness as they acknowledged having breast cancer and requiring treatment for the disease. This may be explained via the diagnostic process and treatment planning being typically undertaken on the same day with surgical intervention following within a week, and thereby the timeframe for being in a state of denial was limited. In the case of early-stage breast cancer the findings from this study suggest that the positive benefits of denial in terms of a buffer effect are consequently short-lived. The influence of taking part in this research study on women's state of denial is also unknown. As noted by Pennebaker, Zech and Rime (2001) writing and talking about a traumatic event may oppose denial by encouraging emotional processing, in this case, of the trauma of breast cancer.

Participants frequently exhibited avoidance rather than denial citing a "knowing" that their breast symptom was cancerous.

*'I think you feel as if you've been hit by a train. All you want him (Consultant) to do is say it's not cancer but at the back of your mind you know it's going to be. You just want him to tell you that it isn't' (Joan; Interview 1; Lines 45-47).*

These women often made reference to cues to such awareness.

*'They don't ring you at home and ask you come in for nothing do they? I think that was a bit of a giveaway. So, although I was in shock a bit of me knew' (Laura; Interview 1; Lines 32-33).*

Accordingly, despite a prevailing hope that breast cancer would not be diagnosed an element of acceptance was common even at this early stage perhaps stemming from having self-identified the change in breast tissue. Acceptance, for Louise, was an automatic process as she did not perceive a choice in doing so.

*'To me cancer was just a word. I'm just accepting it. I'm not really worried. When you go and speak to the doctors and they're telling you everything, and it's only when you come home and you're on your own you sort of think ooohhhh. I mean what can you do, you just have to accept it and hope that the treatment cures everything and then if it comes back, it comes back' (Louise; Interview 1; Lines 137-142).*

While research findings suggest that acceptance at diagnosis is negatively related to distress three months later (Roussi et al., 2007) and up to one year post diagnosis (Stanton et al., 2002) this would seem to be specific to active

acceptance with associated emotion-focused coping. Women who exhibit passive acceptance at diagnosis, as demonstrated in Louise's quotation, have been found to be at significant risk of poor long-term psychological adjustment (Hack & Degner, 2004) and Louise did subsequently develop anxiety and confidence issues.

Other participants described acceptance as emerging a few weeks post diagnosis and seemed to indicate that this followed denial. However, as illustrated in the subsequent extract some women perceived acceptance to be signified by informing acquaintances of their diagnosis and saying "breast cancer" aloud even when their accounts of their experiences indicated private acceptance had already occurred.

*'It's taken me a long time to even admit that I've got it. One of the girls at school said oh how are you, are you alright and one of the other girls said oh have you been poorly and I said yeah I've had breast cancer. Then I though ehhh I've said it, a couple of months down the line, and it was the first time I'd said it...maybe it was acceptance. It was a really big thing for me, it's real now, I had it' (Laura; Interview 1; Lines 345-350).*

The accounts of those women who participated in the present study suggest a far-reaching influence of family, friends, acquaintances, and healthcare professionals in shaping their experiences. The following sub-theme illustrates this impact of others and women's attempts to protect loved ones from the stress of a breast cancer diagnosis and treatment.



### 7.2.3 Protective buffering

While participants made efforts to cope with the shock they were experiencing they simultaneously implemented strategies to minimise eliciting shock in those closest to them. Hiding concerns through protective buffering has been associated with female cancer patient's distress (Manne, Dougherty, Veach & Kless, 1999) yet as in previous research (e.g. Arman et al., 2002) was commonplace for women interviewed for the current study.

*'I think you're sort of brave for everybody else. I had to tell my son, I've only got one son and I had to tell him and of course he was devastated and I said look I'm gonna be fine and I put a front on. I had to go and tell my dad, who's getting on in his years and you don't really wanna tell your dad things like that and so you put a brave face on for everybody'* (Mary; Interview 1; Lines 161-165).

Research indicates that women may conceal feelings and emotional distress to avoid changes in routine patterns of life and uphold a sense of normality (Beatty et al., 2008). Furthermore, in line with the suggestion of Clarke and James (2003) participants may have perceived social pressures to be heroic and cope so as not to be a burden on others. This may be particularly relevant in relation to breast cancer given the positivity associated with survivors of the disease (e.g. Broom, 2001; Farrell Yelland, 2000) which may have led these women to make attempts to be strong and develop beyond their former self. Disguising one's emotions was often undertaken consciously however, Ellen reflected on receiving less empathy from her family following her breast cancer diagnosis compared to previously undergoing a bilateral mastectomy due to a high risk genetic predisposition.

*'I'm very aware that my family kind of think, oh she's done this before so she'll be alright. So, if I am quiet or I am a bit lost in it they tend to want to just jolly me along. So, I've got to put on kind of a front on it as well, I've got to be happy' (Ellen; Interview 1; Lines 275-279).*

Women's suffering has been suggested to increase when it is concealed for example to protect others (Arman et al., 2002) and can lead to some women, such as Ellen, suffering in silence.

*'I've held an awful lot back, I've bottled an awful lot up because I haven't had that place to go' (Ellen; Interview 3; Lines 130-131).*

In conveying their diagnosis to others these women in turn experienced shock reactions directed towards themselves.

*'When I went into work and saw all my friends at work and told them that I was gonna go back in and they were crying and I was saying, "look, I'm fine, don't cry" and I ended up comforting them...and I didn't like that bit, I didn't like shocking people and upsetting people' (Mary; Interview 1; Lines 172-175).*

This was identified as being difficult and distressing which may be explained by the 'looking-glass self' hypotheses which denotes that we understand ourselves by understanding others' reactions to us (Cooley, 1902 as cited in Else-Quest et al., 2009). Cooley argued that the self-consciousness that results from continually monitoring the self from the perspective of others leads individuals to experience either pride or shame. Women's cancer schema as discussed previously may suggest that in seeing the reactions of others women are forced to consider their own perceptions of breast cancer relating to, for example,

mortality and stigma, which in turn leads to stress and anxiety. Yet, contrary to the monitor-blunter hypothesis as distinct personality traits (e.g. Miller, 1987), previously discussed in chapter 5, while participants demonstrated monitoring information pertaining to the reactions of, for example, close relatives and friends, they subsequently enacted blunted responses frequently avoiding informing others outside of their immediate social circle about their diagnosis.

*'I didn't tell many people I was going, because if people start with the "oh are you alright" and all this it upsets you'* (Linda; Interview 1; Lines 84-85).

This finding supports those indicating that women actively avoid people who increase their anxiety and vulnerability via too much compassion as pity from others led to a feeling of being seriously ill (Drageset et al., 2009; Doumit et al., 2010). The topic of avoidance as demonstrated in this theme has however been linked to higher levels of anxiety and depression and may influence women's coping strategies (Donovan-Kicken & Caughlin, 2011). The complex nature of women's relationships with others following a breast cancer diagnosis was also discussed by Bertero and Wilmoth (2007) in relation to attachment validation. They reported that women sought validation from their family and wanted to be truthful yet simultaneously tried to protect others. However, in doing so they perceived a lack of understanding from their family about their experience. Corroborating these findings the present study has found that protective buffering and topic avoidance are additionally undertaken by women's family and friends.

*'Well my close friend.as soon as I came out of hospital she was there and asking if she could do anything and she's remained constant but a*

*couple of other friends either try to wrap me up in cotton wool and won't let me lift anything or they just won't talk about clothes, or anything they think might upset me... and I feel uncomfortable with them because of their reaction to me. I've said a couple of times look I'm fine, I'm still me, there's just a bit missing that's all but they've had great difficulty accepting it and my husband as well. On the up side he looks the same but he tends to "oh don't lift that, don't do that" and I could scream sometimes' (Pauline; Interview 2; Lines 85-97).*

Accordingly, the study participants perceived acceptance as not being restricted to themselves highlighting that those close to them seemed to struggle for a longer period of time to accept the changes brought about by breast cancer. The reactions of others elicited anger in a minority of participants who thereby conformed to Kubler-Ross' second stage of grief. Corresponding to Frank's (1991) notion of the dominating body which is defined by force sees individuals dissociating from their bodies but being linked to others through the displacement of anger against contingency, these women's target was most frequently loved ones. Specifically anger emerged when re-negotiating roles and working towards acknowledging physical limitations. In their efforts to be sensitive to women's needs family members and in particular spouses were often perceived to be a hindrance and participants found others taking on roles associated with their identity difficult.

*'I don't mean to be nasty but they tended to you know what I'm trying to say and actually I did say I'm not an invalid please don't treat me as one, don't smother me, let me find my own way through it. There's times they would say sit down and stop doing things but that's not my way, I'm not*

*that type, I need to be doing things. Obviously I'm not going to be running in any Olympics I still need to try to keep a norm. I had to take it steady at first because of the wound and my arm but when I'm top I'm able to hoover and when I can do it I want to do it. That's what you've got to work out'* (Maria; Interview 1; Lines 266-274).

It is possible that these women's desire for normality and specifically to undertake tasks around the home represented efforts to engage in self-distraction as a means to regulate distress during the acute illness/treatment phase. Post-surgery self-distraction has been shown to predict lower distress three months later (Roussi et al., 2007). However, in developing negative feelings towards others some women interviewed expressed feeling saddened as demonstrated below.

*'Just silly little things you know like I've got a dishwasher but he'd wash the pots. You know I used to think oh my God why are you doing that. Stupid little things but it got to the point, I don't think he knows but I couldn't stand him round me. We've been married for forty two years, I've known him since I was eleven and I've never ever felt like that so that was upsetting me as well you know. I still get a little bit choked up when I talk about it because I know I was being horrible and he was only trying to be so kind but I couldn't cope with it'* (Margaret; Interview 2; Lines 50-57).

This theme has demonstrated that participants' stress reactions during the acute phase of their illness experience included shock and disbelief, and for some women avoidance and/or denial, albeit for a limited time. Individual differences were evident in relation to acceptance however while women

themselves accepted their diagnosis they often perceived those close to them to be experiencing difficulties in doing so. Protective buffering and topic avoidance were used by the study participants to shield others from their emotional status yet these women also experienced these forms of coping directed towards themselves, which occasionally resulted in reactions of anger. Participants' expressions of anger were often underpinned by a period of reflection on having breast cancer between interviews one and two in which women considered existential issues. It is this search for meaning that comprises the following theme.

### **7.3 Search for meaning - existential concerns**

Experiencing existential concerns regarding the meaning of life and facing mortality is widely reported in the literature (e.g. Arman et al., 2002) and the present study supports such findings though goes beyond existing understanding by providing an in-depth insight into these issues and the timings of their emergence. Consequently this theme has been separated into two sub-themes, facing mortality and the following sub-theme, 'why me?'

#### **7.3.1 Why me?**

In assessing women's efforts to make sense of or find meaning for their illness Kernan and Lepore (2009) surveyed seventy two women at multiple time points during the 18 months after breast cancer treatment. Four patterns depicting the search for meaning were identified comprising continuous (44%), exiguous (28%), delayed (15%) and resolved (13%). The results showed no significant concurrent or longitudinal associations between searching for meaning and

made meaning (i.e. finding answers), suggesting that for the majority of women searching for meaning was futile. However, meaning variables were assessed on average 11 months post diagnosis at which point women may have already searched for meaning. This research study was further limited by the ethnic homogeneity of the sample and relatively small sample size. Debating "why me?" and re-assessing their sense of being in relation to others suggests that women perceived themselves differently to before their cancer diagnosis. The following quotation from Laura's first interview provides qualitative support for women's search for meaning. However, it illustrates that this search begins in the acute illness phase and was expected to continue throughout Laura's life as 'why me' was perceived to constitute an unanswerable question.

*'I don't know if everybody says this, but its why me. That's the question. I went out with some girls the other night and there was 15 girls and.I didn't actually go out, I went down to give her a card.I just sat and thought why me, out of everybody. Not that I would wish it on anybody, I don't, but just why me. I think that question will bug me forever. I'll always ask that and I don't know why I bother myself with the question because you never get an answer. It's something I'll never get an answer to. I've just got to get it into my head that it's just one of them things and that's it'* (Laura; Interview 1; Lines 254-261).

Trying to avoid considering "why me" and minimising negative emotions was described by Ellen as a means to protect others and was achieved through attempts to maintain a sense of normality.

*P: 'I think there was a chance that I could have just sunk into self-pity. I could have just sat down and gone why me, it's not fair, why do I have to*

*have this, I thought I'd been there. I needed to kick against that. I needed not to allow myself to go there because that looked really. it looked more scary than going back to work'.*

*I: 'In what way?'*

*P: 'It looked like a pit that I might fall into and not be able to get back out of. I'm a mother of four children, I'm the one that copes with everything. It wasn't for me to fall into that pit and wallow in that black mist so having to concentrate on something else, having to get up, having to go, having to keep going, putting that normality back into my life' (Ellen; Interview 2; Lines 254-266).*

As discussed by Lally (2010) in relation to the period between diagnosis and first treatment such avoidance of introspection may also serve as a self-protecting strategy to maintain women's self-integrity though as evidenced in the current study is not limited to the pre-treatment phase. A prolonged period of reflection and debating "why me" was typically linked to participants contemplating the uncertainty (discussed as part of the final theme in this chapter) brought into their lives by breast cancer and gaining awareness of their mortality.

### **7.3.2 Facing mortality**

Contemplating their mortality was pivotal in women's discussions of their emotional journey, was noted from the first interviews and continued throughout the reflections on their experiences.

*'I feel, I mean you go through days when you do feel really positive, you know I've got to get over it, I've got two kids, I've got to get over it. Then*



*you'll hear on the news that somebody's recently died of it, or whatever, and that really frightens you. It seems to knock you back a bit that.but then the breast care nurse said that for every one you hear on the telly that's died, there's thousands and thousands that haven't and obviously bad news travels better doesn't it'* (Laura; Interview 1; Lines 148-154).

Indeed, while the majority of participants reported immediate fears of death, aligned with their cancer schemas, they simultaneously implemented coping mechanisms to manage death anxiety which supported a life view with hope. This supports the proposition of Lazarus (1999) who argued that hope and fear are intertwined and future-oriented.

Learning of the death of other individuals to breast cancer via the media increased participants' anxiety yet rationalising such loss by reflecting on improvements in treatment regimes and knowledge of other breast cancer survivors facilitated coping.

*'You meet people and they say 'I had it twenty five years ago' and you know things have improved massively in that time and things are getting better and better. This woman I know who's had it twenty-five years, she goes swimming with the kids, and she wasn't given radiotherapy and chemotherapy then because it wasn't given as a matter of course and she's fine, so I should be fine'* (Laura; Interview 1; Lines 162-167).

A frequent reaction by women in the current study supports a strategy of avoidance, also noted by Drageset and colleagues (2009), with women making concerted attempts to avoid thinking about mortality and the possibility of not being cancer free. Cognitive avoidance coping style prospectively predicts emotional distress (e.g. Stanton & Snider, 1993) though rather than being a

negative coping strategy such avoidance seemed to enable these women to minimise distress and facilitated positivity and cognitive restructuring.

*'I think the experience of the cancer itself is frightening because you don't know whether it's gone and they can't give you a test to say it's gone to anywhere else. So, that's frightening, has it gone somewhere, am I gonna be here tomorrow, that has crossed my mind and then I've wiped it out because I don't want to think that way. The experience of all the treatment I actually can't fault any department at all, wonderful, the staff have been so supportive, fabulous. It is scary to think that there's something there. Hopefully they've got it all. I try not to think what if. I've got too much to do, too much to do, too much to see. I like hoovering (laughing).actually it's the only thing that's made me feel better, getting the hoover out' (Amanda; Interview 1; Lines 256-265).*

The above quotation further illustrates how the study participants emphasised the expertise and support provided by the healthcare professionals involved in their care and how women resorted to the everyday activities undertaken prior to diagnosis in order to elicit coping with the difficulties of their experience. It is also plausible that to some degree these women's avoidance may be influenced by the lack of symptoms experienced prior to diagnosis.

*'I think when I look back now.at the time I couldn't see that but now I can see that if I hadn't had it done (breast surgery) I might not have been here in five years time. It's quite frightening to think that you've got something growing in your body and you feel fit and healthy and it's hard to get your head round the fact that it could kill you' (Gillian; Interview 1; Lines 360-364).*

As a consequence of feeling healthy many participants struggled to face mortality issues.

*'I don't dwell on.well I try not to dwell on.like if you die, I try not think about that. At the moment I think I feel well, I haven't got it so just get on with life. I mean I've said this all along, you can't change it. It's happened and you can't change it so you've just got to move along with it'* (Mary; Interview 2; Lines 150-154).

In addition to women's desire to be happy a belief in fate or a higher power was among the multiple strategies participants utilised to manage death anxiety.

*'Maybe I could've died with it and who's to say it's not gonna come back but it doesn't do well to dwell on that because the days I do dwell on it, I'm very, very miserable and I don't want to be miserable. I don't want to be unhappy so I just try to take things as they come and I believe that what will be will be and I think well there must have been somebody up there looking after me to send me for that mammogram'* (Margaret; Interview 1; Lines 152-157).

While coping through religion is one of the most prevalent strategies reported by cancer patients (e.g. Zwingmann et al., 2008) in the sample recruited for the present study few women made reference to such coping. Though not explicitly stating that 'God' was perceived to be in control of illness and its outcome as has been reported elsewhere (e.g. Doumit et al., 2010; Shaw et al., 2007) the implication of using prayer to facilitate recovery is suggestive of a role for 'God' in explaining breast cancer. Above all the participants faith engendered hope which is viewed by some researchers as a coping strategy in itself (e.g. Stanton et al., 2002).

*'I'm on the sick list at church so I've got everybody praying for it'*  
(Amanda; Interview 1; Lines 243-244).

However, such quotations illustrate a sense of having little or no control over breast cancer and death and many women interviewed held a fatalistic perspective, one that can be likened to an external locus of control.

*'Because of the experiences I've been through before, because I'm a fighter, I don't give in. Yes I know it kills people but so does crossing the road. I try not to worry about things that I can't totally control and it's something that you can't totally control'* (Pauline; Interview 1; Lines 320-323).

Unrealistic optimism (Weinstein, 1983) was additionally described by several participants though the complexity of this strategy is illustrated below.

*'It is a bit frightening because you never think it's gonna happen to you, it's always the person next door and not yourself. I still think now well, I'm not gonna die with it, I'm sure I'm not going to die with it, it's going to be the person next door who does. It will never be me. so I try to think like sensibly and try not to worry about it'* (Margaret; Interview 1; Lines 161-165).

Accordingly, while many participants attempted to distance themselves from breast cancer they did not necessarily deny having the disease.

Research has shown that no matter how positive women try to be, negative thoughts often remain and the frightening prospect of metastases and death leads some women to mentally prepare for the worst (Drageset et al., 2009). According to Folkman and Moskowitz (2004) this can represent future-oriented

coping reflecting efforts to save strength to deal with events that will occur with certainty. Louise was one of the few women to accept her mortality and diagnosis relatively early in her journey.

*'I'm not sort of frightened.it's an awful thing to say but everyone has to die at some time and I feel fortunate to have lived this long. I think it's just so awful if a young person gets it because they've got all.all their lives to think about it coming back but at my age.you've sort of lived your life'* (Louise; Interview 2; Lines 287-291).

In doing so some participants such as Rose were able to reflect on their life and make changes for the future.

*'It does make you look at life differently and think you're not here forever and you've got to make the most of the time you have and enjoy life and you also look at death and think yeah I could cope with that. You know really, it's an awful thing to say, but you think well I've had a good life and I've done this and done that. I mean it would be awful to die now, nobody likes the thought of dying but you convince yourself that if that happens it won't be such a bad thing really. It's strange really, I suppose you think more about the people who are left behind because it's them who have to continue on. It certainly makes you look at life'* (Rose; Interview 3; Lines 55-63).

In support of a qualitative review (Bertero & Wilmoth, 2007) as participants sought meaning in their illness experience an awareness of mortality and fear of death often led these women to review their life and re-order life priorities. In reflecting on their lives and the ongoing impact of breast cancer beyond the acute phase women frequently entered a state of psychological vulnerability

and disorientation which was particularly pronounced during interview two and which constitutes the next theme in this chapter.

#### **7.4 Psychosocial distress and coping mechanisms**

The term 'psychosocial distress' was conceived to reflect a broad set of concerns and refers to a continuum of responses ranging from feelings of sadness and vulnerability to disabling problems such as depression and anxiety (National Comprehensive Cancer Network, 2008). As highlighted in chapter 3 breast cancer can result in a complex array of physical and psychological effects including anxiety, depression and decreased functioning which negatively impact on women's quality of life (e.g. Al-Azri et al., 2009; Glanz & Lerman, 1992; Salonen et al., 2010). Similarly, Chen and Chang (2012) reported negative feelings and emotions related to mental distress in a sample of Chinese cancer patients from diagnosis to treatment completion. In support of these findings and in accordance with Engel's second stage of grief the study participants frequently discussed experiencing a range of psychological consequences. These included depression, disorientation, and changes to their personality, as well as coping through positivity. These reactions, which form the sub-themes of this theme of psychological distress and coping mechanisms, were predominantly recorded during the second interviews when adjuvant treatments were underway. Higher levels of distress have been found in patients undergoing a longer course of treatment for breast cancer compared to those women who are treated with surgery alone (Tuinman, Gazendam-Donofrio & Hoekstra-Weebers, 2008). Experiencing difficulties in coping were regularly reported though some participants highlighted that for them this did not constitute depression.

*'I had a real period of not depression but I couldn't cope. I just felt like I couldn't cope with anything. If I got the slightest little thing that was a little bit of bad news or sort of oh anything, I just couldn't, I was in floods of tears and I just couldn't cope with anything'* (Gillian; Interview 2; Lines 130-134).

All women exhibited distress post diagnosis though in support of prior research findings a subset of women described experiencing depression (Fann et al., 2008) and this is discussed in the following sub-theme.

#### **7.4.1 Depression**

Some participants perceived they would experience depression following diagnosis, often on the basis of the reactions of others, and made efforts to engage anticipatory coping strategies at a very early stage. Linda, for example, believed that remaining active and having the support of her husband would be protective of her psychological well-being.

*'People kept saying to me you'll be depressed but I haven't really been depressed because he (husband) like fetches me out of it. That's not to say there aren't little times with the death of my other husband, which was the July and I really felt it then I could have been but I made myself active'* (Linda; Interview 1; Lines 204-208).

However, as formerly identified via numerous studies depression was one psychological issue reported by the women interviewed for the present study (e.g. Badger et al., 2007; Burgess et al., 2005). The consequences of depression post breast cancer diagnosis may extend to mortality as a large population based study reported an increased risk of death by five years in

women scoring high on depression following diagnosis though this conclusion requires caution given small participant numbers (Watson, Haviland, Greer, Davidson & Bliss, 1999). Kubler-Ross (1969) proposed depression to be a discrete level of her grief model though differentiated between reactive and preparatory depression. In the present study reactive depression transpired with women's realisation that they had been diagnosed with a serious illness and following episodes of change such as breast or hair loss as feelings of hopelessness and helplessness emerged with a sense of lost control. Having experienced breast cancer previously Sarah had an awareness of the emotional reactions to be expected at various points in the healthcare trajectory.

*'Vulnerable. Actually quite fragile psychologically...and physically. I think they're both at about the same level out of ten with one being the lowest level of fragile I think I'm about a four psychologically and physically whereas normally I think I'm up to about a seven or eight. I feel fragile and almost aware of the impact on me in terms of erm.reactive depression has come on at times but I've been aware of that, just reacting to the situation that I'm in. It passes quite quickly, it doesn't stay with me' (Sarah; Interview 2; Lines 112-118).*

While for Sarah episodes of depression remained reactionary for several other women preparatory depression (Kubler-Ross, 1969) was evident. This prolonged period of depression occurred as participants gained a realisation that breast cancer and its physical and psychological impact would have a prevailing effect on their lives and influence their future through fear and uncertainty. A vast body of research (e.g. Badger et al., 2007; Fann et al., 2008) has investigated depression following a breast cancer diagnosis though this is



dominated by quantitative studies which fail to capture the complexity of this emotional response.

As demonstrated previously Linda actively tried to minimise the likelihood of depression shortly after diagnosis and did not perceive herself to be experiencing depression at that time. Anxiety and depression scores obtained at diagnosis have been found to correlate with such scores 6 months later (e.g. Jadouille et al., 2006) though like other women interviewed for the present study Linda was subsequently treated for depression by her GP.

*'Just of late I've been a bit depressed but to be honest I never cried even after the operation, never cried because my husband kept me going. Then I did a very, very silly thing which I won't do again. I read that interview with Darren Clarke, that golfer whose wife died of breast cancer. He put in it, it was only a DCIS. well that's what mine was and you think uh oh but I went back to the doctors and they put me on, it's only 10 milligram of an antidepressant. So I'm feeling better, I'm sure I am but I did feel a bit depressed. I just think I'm that kind of person. whenever there's trouble I can deal with it but then when it all goes quiet, you know.'* (Linda; Interview 2; Lines 15-26).

The use of a longitudinal approach enabled one of the most striking cases encompassing depression to be revealed. Emma who above all others can be most likened to Frank's (1995) chaos narrative exhibited distress throughout the data collection period as living through breast cancer dominated her life. Her expectation that symptoms of low mood would decrease upon breast cancer treatment completion was unfounded and she experienced great difficulty engaging positive coping strategies.

*'I thought I'd be better when the treatment had finished but I still have a lot of bad days'* (Emma; Interview 2; Lines 32-33).

When immobilised by depression images of activity and fitness may become guilty reminders of what the person is not accomplishing (Charmaz, 2006) and this can be applied to Emma.

*'I used to go (swimming) four times a week and I think that used to keep me sorted with me weight and me tummy and everything and so that's all to pot. Our mam bought me a bather to go with to wear my false boob but I hate it. I'm always worried in case it falls out so I'd rather not go'* (Emma; Interview 3; Lines 82-86).

Ironically while she felt able to discuss breast cancer with the researcher she ceased counselling finding talking about her experience exacerbated her symptoms. Depression remained an issue one year on from diagnosis by which point Emma had begun a course of antidepressants perceiving this strategy as being under her control.

*'I have been to see a counsellor but I found I want to just put it to the back of my head and the counsellor wanted to go over and over it and I couldn't handle that, I don't need that so I stopped going. I thought I don't need to hear this and so I stopped going. I'd rather deal with this myself. I am on antidepressants now'* (Emma; Interview 3; Lines 62-66).

However when questioned about the effectiveness of antidepressants Emma commented:

*'I don't think anything helps does it'* (Emma; Interview 3; Line 70).

In line with the existing literature Emma portrayed several risk factors that are believed to account for prolonged depression including younger age (Salonen et al., 2009), lack of an intimate confiding relationship, and stressful non-cancer life experiences (Burgess et al., 2005). The present study provides qualitative support for results indicating that depression may not be associated with cancer-related factors (e.g. Bardwell et al., 2006) given the variability in diagnosis and treatment regimes of those women affected by depression. Moreover, the influence of subjective psychological variables is corroborated as evidenced by the extensive stressful life events in the lives of those women experiencing depression. It is possible that the period of reflection elicited by breast cancer triggered these women to contemplate their lives including divorce, bereavement, financial pressures and issues with children. The subsequent sub-theme illustrates the disorientation experienced by participants including issues of anxiety, nervousness and loss of confidence.

#### **7.4.2 Disorientation**

Women in the present study considered numerous psychological changes to be influential in how they viewed themselves throughout the year following diagnosis. Nervousness, loss of confidence and an altered personality featured in women's accounts though in accordance with Frank's (1995) chaos narrative discussion of these elements lacked structure. Several participants described becoming nervous and anxious in social situations which was unlike their demeanour prior to breast cancer.

*'I feel like I'm really, really nervous in situations, I'm really. I feel uncomfortable in situations, I don't like to be in big crowds, anywhere unfamiliar and that's not like me at all. So, yeah it probably has changed*

*me more than I think really. Maybe's it could be the hair thing, I've got no eyelashes and things like that, I can't wear any make-up or anything'* (Laura; Interview 1; Lines 277-281).

High levels of anxiety following a breast cancer diagnosis are widely reported in the literature (e.g. Schnur, Montgomery, Hallquist, Goldfarb, Silverstein & Wertz, 2008) particularly in those women undergoing chemotherapy (e.g. Browall et al., 2006). In support of such findings this change was noted most frequently in women having chemotherapy though by their final interviews women had sought strategies to facilitate coping with the psychological as well as the physical aspects of their experience. Louise, for example utilised alternative therapies to enhance her confidence, decrease anxiety and improve her low mood.

*'Well because of these anxiety problems I'm going to continue with these droplets because when I was taking them on a regular basis I definitely found it was a help and I found when I was taking it on a regular basis I found I was more of a happier person. When I was going into shops I was able to look at people whereas before I found it a problem. So hopefully if I keep taking these droplets the anxiety attacks will fade and eventually I won't need the droplets and I'll be able to control things myself. I'm wanting to go back to work erm.to me there's the social side, seeing people on a day-to-day basis.having a job to focus on. At the moment I feel as if want to rest. I don't feel 100% back to normal but day-by-day, week-by-week I think I'll feel happier in myself'* (Louise; Interview 3; Lines 335-345).

Like many other women interviewed Louise's goal was to restore her former self and regaining confidence in undertaking everyday activities was seen to be pivotal in this process.

*'I did lose a lot of confidence, I was just saying this to a friend the other day. When I first came out of hospital after about six weeks I got back into the car and it's amazing how you lose your confidence but obviously that's all come back now'* (Rose; Interview 2; Lines 174-177).

This is further reflected in the following quotation from Susan who aligned her loss of confidence with hair loss. She did nevertheless feel that this would resolve once she returned to work, and a greater sense of normality.

*'I've lost a little bit of confidence in doing everyday things and I don't know whether that's what makes me think I want my hair to get back to a woman's hair style and I want to keep the prostheses in and look like a woman or whether its I'm getting used to these things that I've lost a bit of confidence, I don't know which way round it is. I can't sort that out in my head but I think that once I get back to work I won't have time to even think about these issues and things will just get going again basically so I think work will prove to be quite therapeutic'* (Susan; Interview 2; Lines 93-100).

However, Susan acknowledged that returning to work would provide a distraction and would limit the time she had to reflect on her experience. Avoidance was a common strategy used particularly by participants who were employed though they did not seem to denote a lack of acceptance but a desire to portray a different, healthy identity.

*'I put it into little pockets so that's the appointment and I've got to deal with that and then that's locked away and I put it away and I don't deal with that.compartmentalise.its come now.so it all goes away and I kind of leave it. I don't think it's particularly healthy.and I'm working too hard.I go to work, this is a theme that's gone on for over a year.I go to work and become the professional me that doesn't have cancer and doesn't have to think about it. Then I go home.you know I've got a much smaller time to deal with it, think about it or work with it'* (Ellen; Interview 3; Lines 36-43).

Ellen's quotation supports a previous qualitative exploration (Jensen, Back-Pettersson and Segeston, 2000) in illustrating not only avoidance but a sense of striving to go on living and working on the healing process albeit in manageable stages. This Swedish study lacks methodological detail and retrospective data collection (up to seventeen years post diagnosis) limit the study findings though related findings can be seen throughout this chapter. Links between the notion of self and personality (e.g. Snyder, 1974) were particularly striking when participants contemplated loss and this is discussed further in the following sub-theme.

#### **7.4.3 Personality**

Perceiving the loss of an element of their personality was described by numerous participants.

*'I feel like I've lost my zap a bit. I'm a happy go lucky type of person, I'm pretty laid back about things but I feel like I've lost a bit of zap, a bit of personality. I feel.nervous'* (Laura; Interview 1; Lines 271-273).

During interview two Laura described perceiving a loss of self, which contrary to her previous belief had not returned automatically following completion of treatment regimes, though she was more hopeful that she would regain her sense of self in the near future.

*'I definitely don't think I have got my zap back but I'm more hopeful than I was last time I spoke to you'* (Laura; Interview 2; Lines 64-65).

Having discussed this perceived loss in the second interview Laura had subsequently reported her feelings to her friends.

*'I've mentioned it to my friends and they say we don't know what you're talking about because you've never changed so although I feel like nobody's ever really noticed. I've kept it well hidden'* (Laura; Interview 3; Lines 133-136).

Conversely, the change to participants' personalities was frequently noted by family members as illustrated in the following quotation.

*'I mean my mum and dad say I've changed and my husband says I've changed but I don't think I see it myself. It does harden you to other things, sort of toughens you up really'* (Gillian; Interview 2; Lines 222-224).

Changes to these women's personalities continued throughout the year following diagnosis.

*'Well I think I have changed in my personality. I am a lot more quiet. no I wouldn't say quiet because I've never been quiet. I don't argue as much whereas before I would argue my case but now I think I can't be bothered'* (Margaret; Interview 3; Lines 43-46).

Consequently breast cancer can be considered an ontological threat taking away these women's former attributes. However, in doing so many participants developed new aspects of their personality and in feeling like a different person conform to the notion of a radicalised self (Clarke and James, 2003).

*'I think I'm one of these people that likes to please everybody and keep everything just so, so and now I think I'll speak my mind a bit more. I'll still go with the flow but I think I'll be a bit more assertive and I'll do more what I want to do rather than what people expect me to do' (Rose; Interview 3; Lines 202-205).*

Furthermore, a year on from their breast cancer diagnosis the majority of participants were feeling more optimistic and began acknowledging the positive elements of their personalities.

*'Now...on the up. Happy in myself now I've got through it, quite pleased with myself how I've got through it. It's surprising what you can cope with. I think you just appreciate the little things that you took for granted. I think I'm a stronger person. I always have been strong but I know it I think now' (Janet; Interview 3; Lines 178-181).*

Janet's quotation echoes Frank's (1993) self-change narrative of the rediscovery of the self who has always been. Participants' use of positivity and finding benefit in their experiences is discussed further in the sub-theme that follows.



#### 7.4.4 Positivity

A positive psychology of cancer challenges the focus on trauma, distress and negative psychological consequences instead arguing that most individuals find benefits, positive meaning and psychological growth resultant to a cancer diagnosis (Aspinwall & MacNamara, 2005). Throughout the year post diagnosis the study participants were found to engage in positively reconstructing their experience aiming to view events in a positive light and gain perspective on their situation.

*'The brain plays very stupid tricks on you at this time. a lot of this is a mind game, it's like getting across a mine field doing all of this and its. it's your sensible head fighting with your emotional head all of the time. You just have to sit down sometimes and say don't be such an idiot'* (Susan; Interview 2; Lines 135-138).

Positive self-talk was one element in women's use of this active coping strategy that has been found to be effective in managing uncertainty and fears about the future following breast cancer (Manuel et al., 2007). As discussed in chapter 5 survival was of paramount importance for all participants and when discussing their experience women frequently described a process akin to positive self-talk in convincing themselves that they would be one of the increasing number of survivors.

*'I think it's a really, really dark patch in your life, it's a really scary patch in your life. It's a crazy experience that you could never explain to anyone, you could never explain that feeling, that fright but as time goes on I think like. you know people do get better from it and that's what you've got to get into your head'* (Laura; Interview 3; Lines 281-285).

In maintaining a positive attitude the women interviewed sought to identify benefits arising from their experience. Theory derived from positive psychology denotes the possibility that benefit finding may be a personality characteristic given the positive aspects or outcomes consistently seen in some individual's narratives of misfortune or tragedy (Tennen & Affleck, 2002). Alternatively Tennen and Affleck considered the possibility that benefit finding is a representation of an individual's characteristic hedonic level. While some women in the present study demonstrated greater benefit finding than others this often seemed to be a conscious effort rather than a personal trait. Furthermore, as illustrated in the following quotation maintaining a positive stance was often perceived to be a necessity for the sake of others and accordingly may be another form of protective buffering.

*'I can't alter the diagnosis but I can have a positive outlook because we know we're going to have to go through a prolonged period of treatment. I think that helped me to be positive about the treatment, there was no point in worrying about something I couldn't change. For my family as well, I've got two sons at home still. I think I thought right, whatever treatment we need, we've got to have it, whatever the side effects are we'll put up with them. Just be grateful that the treatment's on your doorstep, you don't have to raise funds for it like some people do, let's just get on with it. and I still feel like that now. I mean today I think how awful I feel but at least I'm getting the treatment. Some people wouldn't even have that offered' (Joan; Interview 1; Lines 83-93).*

Benefit finding was frequently related to feeling fortunate to be offered appropriate intervention at a local level as well as the speed within which a

diagnosis was received and treatment commenced. The following extract reveals the reassurance Maria experienced as a result of timely diagnosis and treatment and how in turn this engendered a sense of being lucky.

*P: 'I think the first thing is when you're diagnosed is you want it out of there. It may not be the same for everyone but for me the way it was done, the diagnosis was quick, the surgery was quick and you knew what treatment you were having'.*

*I: 'and do you think that helped, having everything move so fast?'*

*P: 'Oh yes. For me that worked. I think it gave me the satisfaction of knowing that someone was there on my case straight away. If they'd waited I'd have been it's still there and they're not bothered. No, for me it worked. They were there on the ball straight away. It is quick and you have to catch your breath but that's for a second. I feel really lucky' (Maria; Interview 1; Lines 361-374).*

Benefit finding often manifested differently throughout the healthcare trajectory and at the second interview time point this emerged in relation to perceiving hope for the future given the benefit of early identification of breast cancer.

*'I think I've been very lucky, I've been given a second chance to just enjoy our lives' (Gillian; Interview 2; Lines 308-309).*

*'To me it means that I'm very lucky that it's been detected because there's lots and lots of women out there who are walking around with a death sentence and they don't know they have it' (Amanda; Interview 2; Lines 342-344).*

These findings typically emerged following greater reflection and attempts to manage mortality issues. However, for Ellen who had lived without breasts for over a decade following a bilateral mastectomy for high risk genetic screening positively restructuring her experience began during the first interview with reference to the ease of detection of the breast lump.

*'Initially I felt like I'd been kicked in the guts. I did all that, I've lived like this for 15 years and it's still here, how cruel is that. It can't be that cruel but having spoken to the Consultant she's said it's actually saved my life because we would never have seen it through breast tissue, the lump was tiny. So, I suppose it's kind of saved my life. I still haven't got my head around it all'* (Ellen; Interview 1; Lines 115-119).

Feeling lucky that the cancerous tumour was encapsulated and that chemotherapy was not necessary were further elements in participants' accounts at this stage.

*'I think with everything happening so quickly you don't have time to really think about it and I think the type of cancer I had and I was very, very lucky because it hadn't spread anywhere. I just think in one way I've been lucky to have had the type I've had rather than you know, have to have chemotherapy and everything else, you know losing your hair'* (Margaret; Interview 2; Lines 181-185).

In the phase of early illness patients may try to make comparisons to frame their experience (Charmaz, 2002) and comparison to others who are perceived to be in a worse situation may help to enhance women's self-esteem. For Amanda comparison was particularly pertinent:

*'A friend of mine actually died from an after effect from the chemo, from an infection so I do consider myself very, very lucky' (Amanda; Interview 3; Lines 168-169).*

Furthermore, the participants compared breast cancer to other former or ongoing ailments or illnesses. However unlike in the study of Doumit and colleagues (2010) in which cultural factors played a substantial role in these comparisons women in the present study emphasised the negative impacts of their long-term conditions and in turn the relatively short-term effects of breast cancer.

*'As far as work goes it's the shoulder rather than the breast cancer that's keeping me away. I've had surgery and there's nothing more they can do and I've had such disturbed nights because I just can't get comfortable in bed. The pain is terrible so because of that the future is uncertain but the way my husband is I'll probably be glad to be at home. It's a funny way of looking at things but maybe this is a roundabout reason why it's happened' (Joan; Interview 1; Lines 349-355).*

In support of Leventhal's Common-Sense Model (Leventhal et al., 1980) Fiona reviewed her somatic state associated with breast cancer and compared this and associated representations of breast cancer with her previous diagnosis of multiple sclerosis. As such she coped by approaching experiencing breast cancer in a positive way and described benefits that she perceived as being a direct result of taking Tamoxifen.

*'I'm more concerned with what I've got, with the MS. This is more my concern because I know for a fact there's no cure for MS. Even the breast cancer nurse said you're taking everything too good, when she*

*came to see me in hospital and I said well I know you can get rid of this but you can't get rid of this (MS). So, really the breast cancer, yeah I was frightened but I thought it's not that bad and when they said I've got the all clear I thought what was I worried about. My attitude is be positive, always think positive and the only thing I can say about breast cancer is that they've put me on Tamoxifen for five years and I feel great on it. To me, it's helped my MS. I was walking on two sticks, now I'm down to one stick' (Fiona; Interview 1; Lines 105-115).*

Women with a diagnosis of multiple sclerosis who are being treated with immunosuppressive treatments have been found to have an increased risk of breast cancer (Lebrun et al., 2008). However, possible improvements in MS symptoms as a result of Tamoxifen are yet to be studied. Fiona represents the epitome of positivity and for her breast cancer did not constitute a major life event given her beliefs and other illness experiences.

Meta-analyses have linked positive affect/optimism, well-being and health (e.g. Rasmussen, Scheier & Greenhouse, 2009) however methodological issues often limit the conclusions that can be drawn. Similarly, research investigating the outcomes of benefit finding are inconclusive as while it has been linked to better psychological adjustment including lower levels of distress other studies report no association and even negative relationships to adjustment (Coyne & Tennen, 2010). It is believed that this contradictory evidence base may be explained by the non-linear relationship between benefit finding and adjustment to breast cancer (Lechner, Carver, Antoni, Weaver & Phillips, 2006). Nonetheless, cultural beliefs and media portrayals of cancer support the notion of a positive attitude and character strength, often termed "fighting spirit", as

beneficial in coping with the disease (e.g. Farrell Yelland, 2000). However, this may have negative consequences (e.g. Broom, 2001) particularly for those women who struggle to maintain this strategy (Lorde, 1985).

Having a "fighting spirit" has not been found to be influential to overall length of survival following a breast cancer diagnosis (Watson et al., 1999). Controversially, the authors concluded that women could be "relieved of the burden of guilt that occurs when they find it difficult to maintain a fighting spirit" (Watson et al., 1999; p.1335). This notion was later refuted by Greer (2000), one of the co-authors of the original paper, who argued for the importance of encouraging cancer patients to maintain this positive outlook. A systematic review has since found little evidence of the influence of psychological factors and coping styles on cancer progression and survival (Petticrew, Bell & Hunter, 2002). These results are consistent with a study specific to women with early-stage breast cancer reporting that fighting spirit conferred no survival advantage (Phillips et al., 2008). While none of the women interviewed for the current research expressed beliefs linking positivity and survival the findings suggest that even in the most difficult of circumstances women perceive it necessary to portray a fighting spirit of optimism and determination to survive, albeit for the benefit of others. Moreover, as breast cancer disrupted these women's lives and led to life-long change to the self, maintaining positivity became an evolving process as they adapted to emerging issues throughout the year following diagnosis.

## 7.5 Incorporating change following disruption to the life trajectory

In accordance with Engel's final stage of the grief process this study has found that one year post diagnosis women had begun a process of resolution and began to reframe their lives and make changes for the future. Supporting the writings of Bury (1982) and Frank (1997) breast cancer was found to constitute a biographical disruption as participants' stories of their past, present, and future were altered by their experiences. Stacy (1988) noted that illness narratives contain a before and after quality with an idealised past that is unproblematic and taken-for-granted. Participants' strive for normality would seem to corroborate this latter point and in line with Charmaz's (2002) viewpoint looking to the past may be undertaken as a frame of reference as because of uncertainty women felt unable to look to the future. The dichotomy of life as two parts is particularly evident in the following quotation from Laura's final interview wherein she uses breast cancer as a point of reference in her life.

*'I think it's like...like say if there was a bridge and I feel as if part of my life is going to be on that side of the bridge and part of it is going to be on this side of the bridge. Even if someone says something now I think was that before I was bad or after?'* (Laura; Interview 3; Lines 344-347).

Accordingly, these women accepted such disruption to their life trajectory (Strauss & Corbin, 1989) acknowledging that their lives would be forever changed.

*'It's been an emotional rollercoaster and I do get weepy about things sometimes. It is a life changing experience and you have to go on don't you and do the best you can in your own little way'* (Jenny; Interview 3; Lines 181-184).



In the context of cancer survivors Drew (2003) described this as "biographical revisioning" (p.181), a process which becomes necessary given threats to self-development imposed by the limitations of illness and/or treatment. As has been shown in the preceding data chapters the study participants made changes to their lives in terms of, for example, body management yet their accounts also sustain the notion of post-traumatic growth embraced by positive psychology (Coyne & Tennen, 2010). Specifically, the present research supports Frank's (1991) proposition that illness provides an opportunity to change behaviour, re-assess priorities and reform relationships. The former of these is depicted in the first sub-theme of this overarching theme of incorporating change though focuses on health-related behaviour change.

#### **7.5.1 Health-related behaviour change**

As discussed previously breast cancer elicited behaviour change towards the monitoring of breast health for some participants though was not the sole alteration to behaviour stemming from the re-assessment of priorities. In support of the aforementioned study of Jensen and colleagues (2000) one year on from diagnosis participants were engaging in natural coping strategies to promote a healthy life.

*'I'm my priority now, my health is my first priority. I'm doing the Race for Life in June with my sister'* (Jenny; Interview 3; Lines 44-45).

Several women including Jenny reported their health to have become a priority and consequently began undertaking health protective behaviours such as increased physical activity. A recent meta-analysis reported statistically significant and moderate effects of exercise interventions on depression,

fatigue, body image and health-related quality of life (Duijts, Faber, Oldenburg, van Beurden & Aaronson, 2011). In the current study engaging in exercise was deemed to reduce the potential for recurrence and as such may relate to Kubler-Ross's (1969) stage of bargaining wherein individuals engage strategies to bring about a longer life. Such behaviours were also used as a coping strategy to manage treatment side-effects which may explain the observations of the aforementioned meta-analysis.

*'I got a lot of joint pain so I went on the Tamoxifen website and it said that exercise was good so I've joined a gym and that has made a massive difference. It's given me energy and made me feel fantastic. When I was reading up about breast cancer it said the chance of it re-occurring was less if you're active so I think going to the gym can't do any harm' (Mary; Interview 3; Lines 12-16).*

Equally, focusing on physical activities such as exercise are commonly reported coping strategies for taking the mind off life-threatening emotions (e.g. Giske & Artinian, 2008; Manuel et al., 2007) which may have been elicited by fears of recurrence. Furthermore, fitness activities may constitute a means of preserving life by regaining health, can promote independence, and may become a preserving self or allow for the development of an improved self (Charmaz, 1987).

Similarly, alterations to diet were put in place to improve general health and minimise Tamoxifen-induced side-effects.

*'Then with the Tamoxifen tablets it does tell you that you could gain weight so I'm gonna be careful and try to eat salads and things. Erm.but I haven't gone back to sort of eating biscuits through the day*

*as I used to and cakes. I used to eat a lot of those sorts of food so I'm glad about that so if I can stay off those I might keep my weight down because erm...when I was having the chemotherapy, obviously with having blood tests they must have found out that my cholesterol level had gone higher'* (Louise; Interview 3; Lines 88-95).

Even those participants who had previously been conscious of their eating habits made concerted efforts to increase their fruit and vegetable intake to benefit themselves and their families.

*'I had a good diet before, was always fit and active. I mean I do try even more now, I eat things like blueberries by the handful, broccoli with nearly every meal. Even my youngest son, I read the Lance Armstrong book so he read it was well and peas and carrots are normally his limit but I always put broccoli on his plate and he'll always eat it'* (Rose; Interview 3; Lines 141-145).

Positive self-reinterpretation via adjusting lifestyle including diet and work schedules have been reported as effective strategies for coping with cancer (Chen & Chang, 2012). The present study has found that such findings extend to breast cancer, typically emerge following hospital-based treatment and are implemented by women for the remainder of the year post diagnosis and potentially beyond this point. Shilling (1993) purports that seeking mastery of the body, for example via improving diet, increasing physical activity or electing to undergo reconstructive surgery, may offer certainty in an uncertain world. By taking control of the body, such body projects enable an individual to present an attractive physical image of themselves and accordingly present an attractive self with new activities becoming a marker of the new self (Charmaz, 2006).

Finding something important to live for, gaining insights about life and introducing radical change in life have been previously recorded as elements within women's experiences of breast cancer (Jensen et al., 2000) and are considered further in the following sub-theme.

### **7.5.2 Re-defining life priorities and goals**

Women have been found to pay greater attention to life priorities in the time immediately following a breast cancer diagnosis up until breast surgery (Drageset et al., 2010). This research has found that this continues throughout the year post diagnosis. Such strategies are said to be productive in coping with stressful events (Folkman & Moskowitz, 2004). Deciding to move home was one way in which two participants quite literally re-drew their "destination map" (Frank, 1995; p.89).

*'It has been big life changing in one way and another. Well it's made me want to go to a smaller property for a start, made me think there's more to life than cleaning up all the time. I used to do the windows every week and now I can't remember the last time I did them whereas when the children were little it used to be washing on a Monday, ironing on a Tuesday and there is more to life' (Linda; Interview 3; Lines 177-182).*

Similarly, by interview three Margaret and her husband had made the decision to move home in order to facilitate achieving life-long goals.

*'I just think I've got a different outlook on life. I mean we're selling the house at the moment, well we've got it up for sale, which I might have never done before... hopefully we'll do a bit of travelling and where*

*beforehand we might not have thought of doing that'* (Margaret; Interview 3; Lines 48-49...53-55).

This suggests that rather than plans being postponed or cancelled as suggested by Frank (1997) once treatment was completed these women often instigated new plans. Margaret's quotation also resonates with Frank's (1995) quest narrative sub-type automythology where fate or destiny is revealed through illness as had she not experienced breast cancer Margaret would not have implemented life changes.

As early as interview one, the participants reported having a different outlook on life which translated into altered priorities most commonly pertaining to work both inside and outside of the home.

*'It's changed my opinion about work because I've worked for thirty odd years and had no time off, apart from holidays of course. When you're self-employed you work all hours and you come home, and it's a family business, so you come home and you're talking work. I've really enjoyed the time off, so I won't be going back to working the hours I was working before'* (Rose; Interview 1; Lines 183-188).

Reducing working hours and having less concern about household chores were the most frequent alterations to these women's lives one year on from their diagnosis. Similarly, previous studies have reported reductions in working hours and voluntary ceasing of employment by women with breast cancer as well as a reduction in the importance of work and ascribing a more balanced approach to life (e.g. Maunsell, Drolet, Brisson, Brisson, Masse & Deschenes, 2004).

*'It puts everything into perspective now, I have a different outlook on life, you think.it's just like.I said the other day, we've just booked a holiday, just for a week and I was thinking I need this doing and that doing but no, no we'll just go for a week's holiday. It'll all be there when I come back, just a different outlook. I don't think you take life for granted'* (Janet; Interview 3; Lines 45-50).

Appreciating life and time with others with less focus on their roles within the home were also noted by Margaret.

*'I don't worry about things as much, I'm more calm. Where I would be I've got to do this today, I must do this today.I'm not like that any more. If somebody comes and I haven't washed the floor, it doesn't make any difference, where before I would be oh someone's coming, I've got to wash the floor. I'm not like that now and I think I appreciate my life more. I appreciate my husband more, the grandchildren more and my family'* (Margaret; Interview 1; Lines 183-189).

Coping through a re-definition of personal values has been proposed to enable the maintenance of a positive self-concept and psychological integrity (Roy & Andrews, 1999 as cited in Drageset et al., 2010). While this seems to be applicable to this study the extracts presented in this theme suggest that breast cancer went further and challenged the participant's notions of the self which as noted by Goud (1995) leads to new insight. Whereas losing their identity within the home and handing over control of traditionally feminine roles, due to the physical impact of treatment, was initially distressing women's re-ordering of life's priorities as illustrated by Margaret indicates that women perceived a new

improved self or supranormal self (Charmaz, 1987) to have emerged from reflection on their experience.

Indeed, Frank (1995) purports that suffering lessens when a person can redraw their life trajectories and visualise a future. These stories of breast cancer providing impetus for change can be likened to Frank's (1995) quest narrative and specifically the sub-type known as 'manifesto' through which illness is a motivator for action. On such self-development of the qualities acquired or realised during illness Frank (1995) writes "what we hear is not people rising above their suffering, but rising in their suffering" (p.66).

In contrast other participants continued to seek normality and did not intend to revise their map for the future. These women may be regarded as rejecting a survivor identity (Kaiser, 2008).

*'I'm not one of these women who says now that I've had cancer and I'm through all of this I want to do all sorts of things like climb Everest or go down the Amazon or tour the world, I just want to get back to normality and pick up with my life where I left off'* (Susan; Interview 2; Lines 168-172).

Kaiser's (2008) qualitative study encompassing thirty nine interviews with American women who completed treatment for breast cancer three to eighteen months previously described how 51% of women perceived themselves as survivors while 49% rejected the survivor identity. Women in this latter group did not want to be part of a social identity defined by illness whereas women embracing the notion of survivor felt empowered by the strength they had found to get through breast cancer diagnosis and treatment. As discussed in the previous data chapters a restitution narrative dominated participants' accounts

of their experiences of breast cancer though as suggested previously women in the present study demonstrated elements of different narrative types throughout their experience often simultaneously. While as illustrated throughout this theme these women may have re-defined their life priorities and goals during the acute phase of their illness, major life changes were not initiated until almost a year had passed since diagnosis. This may be explained by participants' initial focus on treatments and subsequently recovering from medical procedures and regimes. Having time for reflection may be of importance here as until these women had time away from a medicalised routine they could consider little else. Nonetheless, in re-drawing their life trajectories to take illness into account the women in the current study constructed a more flexible self which can be aligned with the postmodern notion of self as changeable rather than static (Frie, 2011). In addition to changing behaviour and redefining priorities, women spoke of incorporating change through reforming relationships and this constitutes the successive sub-theme.

### ***7.5.3 Reforming relationships***

Breast cancer is known to be viewed by some women as an opportunity for personal growth. In a study of 101 breast cancer survivors post treatment 83% identified at least one benefit such as personal growth, greater appreciation of life and/or relationships with others (Sears, Stanton & Danoff-Burg, 2003). Appreciating others particularly family members was evident early in participants' experiences and they frequently reflected on how the experiences had brought their family closer together and had strengthened the bonds between them.



*'The outlook on things, you know, the thing you take for granted, you think let's make the most of this nice day. Actually you find out, I have lots of good friends but I didn't realise how good my daughters were until this year, not just with this but with everything. I've got a real good partner and I couldn't have done without him. It's brought the family closer'* (Janet; Interview 1; Lines 229-233).

Likewise, Mary commented:

*'Well, we were close anyway but we seem to be a lot closer and we do things more as a family. We've had more parties this year than we've ever had (laughing) and we're in touch more. We were in touch quite a lot before but I just think more so now and it's brought us all together'* (Mary; Interview 3; Lines 170-173).

These findings are supportive of a positive impact of social support on the coping process (e.g. Doumit et al., 2010; Holland & Holahan, 2003). Specifically, the support received from the participants' partners was perceived to be invaluable throughout their journey.

*'We've cried, we've laughed, we've shouted.. .but we've done it together. We've talked, we've talked it over and of course we told our son everything right the way along the line as well. So, it's been a process we've gone through together'* (Amanda; Interview 1; Lines 387-390).

Amanda later reflected:

*'At first you're very, very sad, a big sadness comes over you and then you learn to deal with it and as long as your family's taken into that big*

*loop right at the beginning then they can deal with it with you'* (Amanda; Interview 3; Lines 179-181).

Consequently, for those women who had a supportive partner breast cancer became jointly owned (Illingworth et al, 2010) and experienced throughout the year following diagnosis. Linda described how her husband was able to identify when she was feeling low and would use humour to lighten the mood.

*'When I came home there were some blue tits in that box and Brian says aren't we lucky, he says, we lose one tit and we get another four (laughing). He helps me snap out of it'* (Linda; Interview 1; Lines 208-210).

Expressing their appreciation for the support they had received was also noted to be a component of this theme during the final interviews.

*'I think you're more able to express things that matter to you more and not just to your family but to your friends. You tend to value them and let them know what they mean to you. I think by doing things for your friends they know what they mean to you I don't think you ever really vocalise that and I don't know how many times I've now said to my friends "I don't know what I would have done without you"'* (Joan; Interview 3; Lines 127-132).

To provide some contrast relationship breakdown occurred for one participant by interview three which she perceived to be a direct result of the strain that experiencing breast cancer had upon her marriage. Specifically, a discrepancy between their responses to breast cancer was influential as while Ellen looked

to incorporate breast cancer into their life story her husband did not deem this to be necessary preferring a strategy of avoidance.

*'I think there's just been so much stress and so much pressure and he hasn't been there, he couldn't pick any of it...and in fact he held me back...he wouldn't let me look at it'* (Ellen; Interview 3; Lines 88-90).

Patient's experiences have been identified to seem more negative if partners are withdrawn (Pistrang & Barker, 1995) and in line with previous research Ellen reported her husband engaging in problem minimising and insensitive comments (e.g. Dunkel-Schetter, 1984; Dehle, Larsen & Landers, 2001).

*'He once told me we were talking about how it had been and what it had been like and the first surgery I had and he told me that we were very lucky because God had given him the ability to still love me and that you know sometimes it would have been nice to have a woman that had breasts but God had given him this ability to love me still'* (Ellen; Interview 3; Lines 476-481).

Partners difficulties understanding women's feelings can exacerbate negative emotional changes (Fobair et al., 2006). It has been argued that these problems are more prevalent in women with pre-existing anxiety, depression or sexual dysfunction, which may be applicable in Ellen's case given her decade of managing breast loss, however these are issues for a large proportion of women with breast cancer (e.g. Fobair et al., 2006). Moreover, Ellen's perceived need to stay engaged with breast cancer yet being hindered in doing so by her husband may have limited her opportunities for emotional expression and in turn positive cognitive restructuring. The emotional responses of others living in the patient's environment have been suggested to decline three months

after surgery which may also be related to the distress seen in some women (Stanton et al., 2000). There was a profound change in Ellen by the third interview which she admitted had been highlighted by several friends and colleagues. When asked about this altered self Ellen commented:

*'I guess I'm coming to the point where I've got it a lot more into perspective, I've got my future, I'm looking forward to my future. I can kind of notch it up as another experience...There's not one part of me that will say I don't love this guy because I do...I love him dearly but I've suddenly become strong enough to say that's not enough, I need more than that'* (Ellen; Interview 3; Lines 451-453...490-493).

Recognising her own needs and looking to her future were central in Ellen gaining psychological strength from her experience. This theme has shown that the women interviewed perceived breast cancer to have disrupted their lives and changed their sense of self through altering their perspective on life, health-related behaviour and appreciation of relationships. However, although participants emphasised the positive nature of such change, the final theme outlines the enduring psychological impact of breast cancer.

## **7.6 Untidy ends**

Although the latter theme shows how women were able to re-draw their life trajectories and re-develop the self at varying points following diagnosis Frank (1995) recognises that "tidy ends might not always be possible" (p.183). This is reflected in the first of two sub-themes outlining participants' ongoing uncertainties about the future.

### **7.6.1 Ongoing uncertainty & the omnipresence of cancer**

Patients who have been diagnosed with cancer typically experience uncertainty as a reaction to their disease situation (Penrod, 2002). Conceptually, uncertainty can be described as the omnipresence of cancer (Shaha & Cox, 2003), a reaction to the life-threatening aspect of a cancer diagnosis. Participants' reflections on issues of mortality during the initial months following diagnosis led to an awareness of the insecure nature of the body and self. Mishel's theory of uncertainty in illness operationalises uncertainty as "existing in illness situations that are ambiguous, complex, unpredictable and when information is unavailable or inconsistent" (Mishel, 1988; In Smith & Liehr, 2003, p. 25). It is seen as a result of stressors that affect the person concerned directly. An individual's appraisal of these stressors will lead to either a positive (opportunity) or negative (danger) identification resulting in coping strategies which lead to an adaptation to uncertainty (Smith & Liehr, 2003). Evidence suggests that uncertainty is linked with lower quality of life in women with breast cancer (Gaudine, Sturge-Jacobs & Kennedy, 2003).

Moreover, a literature review exploring aspects of uncertainty experienced by cancer patients suggests that three themes depict this concept (Shaha et al., 2008). Uncertainty due to limited or a lack of information, uncertainty regarding treatment choices, and uncertainty pertaining to everyday life and coping with the illness were identified, though the search identified only eight articles published between 1994 and 2007 in relation to breast cancer. The authors concluded that this area of research remains limited and lacking in-depth longitudinal qualitative exploration considering how and why uncertainty changes over time. In support of previous research this study has found that feelings of uncertainty constituted a prevailing experience in breast cancer

(Shaha et al., 2008). Uncertainty about treatment effects was common early in women's experiences as illustrated by Susan.

*'It is quite scary because you know you're going forth on all these treatments and it seems like it will be a very long haul and at times it seems like you will never get to the other end. Physically, it hasn't been anything like I expected but mentally it's a minefield. You can't even gear yourself up for it. you might be told to wait. Just because you got side effects with the last treatment doesn't mean you will with the next. You never know what side effects you will have'* (Susan; Interview 1; Lines 161-167).

However, by far the most common focus of participants' reflections on uncertainty was, linking with existential concerns particularly regarding mortality, was the possibility of having a recurrence. The cognitive avoidance coping demonstrated by numerous women in this study has been found to predict fear of cancer recurrence one year after a breast cancer diagnosis (Stanton et al., 2002). While recurrence is not a certainty it was not knowing that influenced these women's lives throughout the year following diagnosis.

*'I don't think I really thought about. I mean initially you think oh I'm gonna die and then you think no I'm not I'm having treatment and now I'm at the stage when I'm thinking what if it comes back'* (Mary; Interview 3; Lines 54-56).

Corroborating previous research findings (e.g. Bottorf et al., 2007; Browall et al., 2006) the uncertain prospects of cancer spread and recurrence influenced the participants' lives and their ability to cope, specifically impacting on their

capacity to put breast cancer behind them. For Joan uncertainty about spread as a result of positive lymph node identification permeated her daily life.

*'I've always got it at the back of my mind, these glands that were affected under my arm' (Joan; Interview 2; Lines 73-74).*

The possible recurrence of breast cancer has been reported to be the single largest concern, out of a possible twenty eight including body image, pain and rejection, among 223 women with early stage disease within the year post treatment (Spencer et al., 1999). Similarly, all women in the present study contemplated the possibility of recurrence though additionally aligned this with fear and anticipated it to be a lifelong concern.

*'It's certainly frightening, and I think for the rest of my life I'll think about it. I will be feeling for lumps here and lumps there, and probably if I get a pain somewhere and I can't put my finger on what it is it'll always be in the back of my mind that I've had cancer and it could return, where before I never thought about it at all' (Margaret; Interview 2; Lines 173-177).*

Margaret's quotation further supports the notion that common health problems may be perceived as sinister risks that reinforce the omnipresent nature of cancer (Shaha & Cox, 2003). Increased body awareness and in turn seeking medical attention for ailments where previously a greater period of waiting would have ensued was often described. However, achieving a balance between concerns about recurrence and living one's life was also discussed by Maria as being necessary.

*'I do the checks and if I find anything I'll be straight there no matter what. I think I might be say if I suddenly started getting a lot of back pain. see I was the type of person it would just be a pulled muscle but now I think it'll be wait a few days and then go to the doctors whereas before oh it'll work out itself, wear it off, but because I won't be seeing anyone to say yes you're fine, I would go more. I'd be more aware and not leave things, I will get checked just in case. That will always be there. just in case. I'll go and get checked. just in case. I won't let it rule my life. I won't go through the rest of my life thinking the least pain, is it that come back but if I'm ill and it's not sorted I'll go to the doctors instead of leaving things' (Maria; Interview 2; Lines 297-306).*

These findings can be likened to the conceptualisation of abstract and concrete level representations (Benyamini et al., 2009). At an abstract level cancer worries led to a coping strategy of greater attention to bodily changes while at a concrete level identification of a specific symptom (e.g. breast lump), would now lead women to seek immediate medical care. However, obtaining a balance between attending to the body and moving on with life was described as being difficult for many participants particularly while undergoing active treatment.

*'Part of me really doesn't think that I have it any more but obviously there must still be something there but I don't know. I think just to get that scan over and to say everything's gone, there's nothing there. I think at this stage and people I've spoken to say the same, everything you get you think it's that. Every single ailment you get if you've got a headache, it's a brain tumour. Everything you get you put it down to that but then part of you thinks you haven't got it. Part of you thinks you have,*



*everywhere and part of you thinks you haven't. It's still all very muddled I think, really muddled at this point, not quite sure what you think or believe'* (Laura; Interview 2; Lines 134-143).

Around one in five women have been found to have strong worries about their future health at six and twelve weeks post breast cancer surgery (Wade, Nehmy & Koczwara, 2005). The study of Wade and colleagues found denial coping immediately after breast surgery was predictive of future health fears and that this relationship grew stronger over time. A low response rate and relatively short-term follow-up limit the conclusions that can be drawn as does the single-item measure utilised. The current research findings demonstrates the nature of these health worries, that they remain interlinked with the potential for spread and breast cancer recurrence and that these worries remain twelve months on from diagnosis.

It has been reported that uncertainty may appear differently at varying stages of a cancer experience from a weighing up of benefits and side-effects during treatment to a future with hope yet few guarantees following treatment completion (Shaha, Cox, Hall, Porrett & Brown, 2006). This latter component would seem to be supported by the present study as while women expressed concerns about spread and recurrence they did so in the context of living thereby suggesting a prevailing hope for the future. Furthermore, the passage of time was perceived to bring about greater reassurance and in the longer-term regaining confidence in the body.

*'Every single twinge I get in my body I think is it that, is it related? I mean I have spoken to people and they say it will pass, I will get to trust my body again but at the minute I don't'* (Mary; Interview 3; Lines 100-102).

Accordingly, as reported by Bertero and Wilmoth (2007) participants' attempts to resume normality were influenced by their uncertainty about their future life which in turn affected their sense of self. Following the application of Frank's narrative types to breast cancer Thomas-McLean (2004b) argued that although many women strive for full restitution, as has also been demonstrated in the two preceding chapters, this may not be possible given fears of recurrence. Yet, she adds that some women may not want to return to their former self and the increased psychological strength and positive life changing decisions portrayed in this chapter corroborates this notion.

Moreover, the accounts of women in the present study, as demonstrated in the previous quotation from Mary, suggest hope for the future, a strategy that can help individuals to manage the uncertainty of cancer (Giske & Gjengedal, 2007). Women's will to live and desire for normality while making the future meaningful and managing issues of uncertainty and mortality was shown through a grounded theory study with ten Norwegian women with newly diagnosed breast cancer (Landmark, Strandmark & Wahl, 2001). The authors concluded that the will to live encompasses women's ability to cope with existential issues. Data collection took place between four and nineteen months post diagnosis and all participants had undergone mastectomy. Importantly, the current research has found that concerns of uncertainty are equally prevalent in women who have undergone breast conserving surgery. In addition, though hope and fighting spirit to cope with the stress of their experience are evident, issues of uncertainty remained in the participants' minds from diagnosis to early follow-up.

### 7.6.2 Back of my mind

Despite acceptance the participants frequently experienced difficulties re-adjusting their mindset to move breast cancer to the back of their minds.

*'My brain is, I know I've had to try and keep my brain functioning properly to sort all of this out and to actually physically get through it all and so now it is sort of to an extent running in that way, it hasn't, it is starting to come down but it hasn't properly come down so if anything happens...that is not what I'm expecting...that normally would be perhaps a disappointment or an irritation or gosh I've got to sort this out sort of thing, at the moment it is still a major problem because my brain is still running at this high level. Hopefully that will start to come down as well once I get back to work and I've got my job to concentrate on and the people around me as opposed to being here by myself'* (Susan; Interview 2; Lines 306-315).

All participants were forced to acknowledge that their experience would remain part of their future identity despite ongoing efforts to put it to the "back of their mind".

*'I think it'll always be in my head, I do. It's like a scar for life isn't it, you can't stop your head thinking. Obviously it's got to get easier but I don't think I'll ever forget it because things will set it off'* (Emma; Interview 1; Lines 328-330).

By the second interviews the women acknowledged that breast cancer was never far from their thoughts and had a psychological impact on their daily lives.

*'I think what's not normal is it's never ever more than two seconds out of mind, ever. Whatever I do, that's there...it's never...every...I don't know,*

*like the kids birthdays, it was hers in August and it was like please let me be here for the next one. Everything is darkened a bit, everything has that underlying something that and that's what I hope will fade away in the years to come'* (Laura; Interview 2; Lines 185-189).

McCann and colleagues (2010) noted that women experienced difficulty managing ongoing treatment side-effects and moving on from breast cancer and found it difficult to see an end to their experience. The present study provides support for this finding but in addition has uncovered that women perceive others reactions to their diagnosis to be influential in their ability to move on from breast cancer and to regain a normal life.

*'This is going to sound awful again because I shouldn't think these things really, but at the moment people are still coming in and saying "how are you, how are you getting on?" I want life to be, people to say hi, how are you but not referring to cancer and cancer treatments, it just being what we say to one another. So not only I suppose have I put it behind me but the people around me have all put it behind them as well and we're all back to moaning about the trivial things in life that we moan about every day and catch up with the gossip and all that sort of thing'* (Susan; Interview 2; Lines 372-379).

For some participants keeping their experience at the back of the mind ensured mental preparation for a future in which breast cancer may once again present itself.

*'There's a part of me that cannot stop and put it to rest. I've got to stay. it's not that I've got to stay vigilant to watch for it, it's that I've got to be prepared that I might need further treatment or it might return or I*

*might need more surgery. If I've said that's that, it's finished and it re-occurred it would be harder to look at it again'* (Ellen; Interview 2; Lines 203-207).

By interview three women's reflections in relation to this theme showed progression.

*'It's always still at the very back of your mind and I think it always will be but I think it's further back in my mind than it was last time you were here and I'm sure next month it'll be further back still'* (Margaret; Interview 3; Lines 221-224).

Similarly Maria commented:

*'At first it was the getting it off, getting it out, getting it over with. As time's gone on it's a case of its over with now get on with it. It will obviously be there the back of my head and now and again it comes back, to the forefront. Now all the treatments over with its more at the back of my mind and things are back to normal but while you're having the treatments its all still at the forefront. Now and again it springs to mind if you see something on the television, or in magazines or someone brings it up you know but other than that most of the time it's at the back of my head'* (Maria; Interview 3; Lines 64-71).

At this point in their journey the participants reported less focus on experiencing breast cancer and being able to put their illness further to the back of their minds with the passage of time.

*'It's certainly not as at the forefront of my mind as it was the last time I saw you and it certainly isn't to that degree but it is still very much there.'*

*I'd be a liar if I said it wasn't. It's still. I would never say there's a full day goes by when I don't think about it at some point, well more than one point, at a few points in the day. I remember going through a thing where I just couldn't focus or think or anything about anything, it was the only thing I could, that was on my mind every minute of the day. I'd try to distract myself by doing other things but it was just there all the time. but that bits gone'* (Laura; Interview 3; Lines 73-81).

Yet even at this final stage in the year post diagnosis many participants continued to wait for an end to their breast cancer experience and anticipated doing so until all treatments had been completed and/or they had reached the five year marker.

*'Hopefully I'm not always going to think is it going to come back. I think when I've got over this 5 years because they say 5 years don't they. and then I'll have finished with the Tamoxifen, then it'll be over with and I think I'll feel a lot calmer in myself. I think I'll feel more like it's come to a close, I can put a lid on it'* (Jenny; Interview 3; Lines 117-121).

A year on from their diagnosis a future with living at its core was envisaged by all participants to a greater extent than at any other point in the healthcare trajectory. However, this future would continue to incorporate breast cancer at the very least in the back of these women's minds compromising their sense of re-entering the world of the healthy and as such an altered and evolving self. Accordingly, this finding supports the conceptualisation of liminality as being enduring and experienced into survivorship.

## 7.7 Chapter summary

This chapter has shown that upon receiving a diagnosis of breast cancer the majority of participants entered a state of shock and disbelief, the sole exception being a woman who was experiencing a recurrence. While at this time some participants appeared to engage in denial this is short-lived and immediate passive acceptance was not uncommon which may have provided an additional explanation for the role these women assumed in treatment decision-making and their acceptance of medical opinions. Throughout the acute phase participants made conscious efforts to protect the psychological well-being of others. However, particularly for those women undergoing additional hospital-based treatments this was typically reversed with family members trying to minimise the physical strain on women yet this often elicited anger and frustration as changes to women's identity occurred. Within the weeks post diagnosis all participants engaged in reflection regarding existential concerns contemplating 'why me?' and mortality issues. For a subset of women interviewed this subsequently resulted in mental distress including anxiety and depression though general changes to women's personality were frequently reported. Antidepressants and alternative therapies were used to manage symptoms during this time and the majority of the study participants engaged in cognitive reframing to maintain a positive demeanour. A year on from their diagnosis these women had altered their behaviour and outlook on life, had re-ordered their priorities, re-formed relationships and made life changing decisions. However, the ongoing uncertainty brought about by breast cancer and specifically fears of recurrence led them to acknowledge the prevailing impact of breast cancer on their lives as it remained at the back of their mind into survivorship.

Accordingly, in relation to the grief model of Kubler-Ross (1969) the emotional reactions of women with breast cancer may correspond to the stages of denial, bargaining, depression and acceptance. Nevertheless, this cannot be applied to all women as some of the participants in the present study experienced only one stage and those who do go through multiple stages do not always do so in a linear fashion and can experience these simultaneously. The notion of stages fails to account for the complexity within women's responses to breast cancer as although some women seemed to engage in denial they spoke and behaved in ways to suggest the opposite. Furthermore, the process of acceptance was individual and encompassed differing elements given these women's belief system and social support. Examination of these stages has led to an established consensus that not all patients go through all stages and those who do may move forwards and backwards through the stages and while an individual might move through one stage within a few days they may linger in others for months (Lyckholm, 2004). Engel's (1961) theory would seem to provide a more effective framework in which women's emotional journey can be integrated. However the findings of the present study suggest that once again there are exceptions to the proposed stages most notably shock and disbelief which may not be relevant to women experiencing recurrence and denial may not be a feature of this stage for all women.

The themes presented throughout this chapter are not intended to be characterised as a stage model *per se* as while they can be helpful in understanding processes of loss they miss the uniqueness of women's stories. Participants' responses to breast cancer were individual and variation in these women's experiences of the processes categorised as themes as well as the specific timing of reactions was evident perhaps given the multiplicity of



treatment regimes. Consequently, the Shifting Perspectives Model of Chronic Illness (Paterson, 2001) may be applicable. Rather than using terms such as denial, a label which it is argued may be internalised by patients damaging the sense of self and limiting identity re-formation (Telford et al., 2006) it instead recognises individuality in experiences of chronic illness. The model emphasises fluctuations in attention to symptoms over time and considers statements of optimism and pessimism to be indicators of the person's perspective rather than a failing to understand the reality of the disease.

A summary of the findings presented in the data chapters can be found in Appendix 10. The following discussion chapter briefly summarises the key research findings illustrating the inter-relationships between themes and highlights those findings that further our understanding of women's longitudinal experiences of breast cancer. The discussion subsequently considers these findings in the context of current policy regarding breast cancer care as well as theories of self, embodiment, stress and coping.

## **CHAPTER 8: DISCUSSION**

### **8.1 Introduction**

This chapter considers the central themes discussed throughout the data chapters and draws conclusions as to participants' experiences of breast cancer from a longitudinal perspective. Since commencing this research an increasing number of studies have adopted a longitudinal design including qualitative approaches with data collection throughout the year following a cancer diagnosis. While a small number of women with breast cancer are frequently included in the study sample the research focus on broader issues of cancer survivorship (e.g. McCann et al., 2010) or relationships (Illingworth et al., 2010) has limited exploration of women's experiences throughout the healthcare trajectory. Those studies that are specific to breast cancer consider the symptom experience (Tighe et al., 2011) or collect data retrospectively (e.g. Thomas-MacLean, 2004a). The use of hermeneutic phenomenology and illness/treatment grids to support the interview process are unique to the present study and explorations of women's experiences of breast cancer from post diagnosis to early follow-up. Accordingly, the current research has uncovered numerous themes that constitute the elements of the study participants' experiences of breast cancer and which represent issues pertaining to the medicalisation of breast cancer, the body, and the mind.

In adopting a longitudinal approach this study adds to existing understandings of the illness experience and specifically breast cancer by revealing the emergence and development of the themes identified throughout the year following diagnosis. While some themes (and particularly sub-themes) were distinct to one period of time (e.g. role in the treatment decision-making process

and getting rid of it were relevant in the two to three weeks following diagnosis) other themes emerged post primary treatment (surgery) and extended throughout the healthcare trajectory (e.g. dressing the body to accommodate breast surgery and untidy ends). Furthermore, several themes (e.g. waiting, cancer schema and responsibility for breast health) manifested throughout the data collection period and were influential in shaping women's experiences of breast cancer prior to diagnosis and potentially beyond early follow-up. Nonetheless, the present study has additionally uncovered variation in the ways in which the participants' experienced breast cancer over time in the context of the emergent themes. Women's biography, medical history and current diagnosis, prescribed treatment regime, financial circumstances, perceptions of cancer and social support influenced their responses to the multifaceted experience of being diagnosed with, and treated for, breast cancer.

Consequently, participants' experiences of breast cancer can be viewed as evolving and as eliciting concerted efforts to cope with changes to women's perceptions of their body, self, identity and sense of embodiment. In what follows the inter-relationships between themes are considered in order to reveal the 'whole' experience in the context of relevant self, embodiment and coping theory and current healthcare policy. Specifically, on the basis of the research findings, policy developments and theoretical perspectives are evaluated in terms of their applicability to the breast cancer illness experience. The methodological approach including the use of hermeneutic phenomenology and illness/treatment grids is assessed as are the limitations of the study. Finally, directions for future research are suggested and the implications of the study results for the care of women with breast cancer are considered.

## **8.2 Implications for breast self-examination**

Given the nature of the sample, the participants described their experience of breast cancer as beginning prior to diagnosis with the detection of a breast symptom, most commonly a self-identified abnormality. Those women who had begun to experience pain in the breast, had undergone treatment for prior breast disease and/or conducted regular breast self-examination (these were often related concepts) typically consulted their GP immediately. However, other participants reported waiting, often for several weeks, before seeking medical advice.

A survey, co-funded by Cancer Research UK and the National Cancer Action Team, has recently been announced with the aim of investigating the nature and duration of symptoms experienced prior to diagnosis in approximately 2500 people covering 22 types of cancer (Department of Health, 2011). While this may help to establish at what point and with what symptoms individuals seek help it is unlikely to uncover the reasons for delay. The present research has found that disease specific factors influence women's help-seeking following detection of a breast symptom and these aspects may be key to successfully promoting behaviour change. It emerged that some participants were aware of the benefits of early diagnosis yet consciously chose to wait due to other responsibilities and commitments, the misattribution of breast abnormalities and their breast cancer schema, specifically, a lack of symptoms that they associated with breast cancer. Crucially, this research has additionally uncovered that these women rarely examined their breasts due to unrealistic optimism and perhaps given the prevalent view of breasts as an external organ that was no longer required following child-rearing. Moreover, these women engaged in a long-term process of self-monitoring prior to help-seeking.

Accordingly, although the benefits of breast self-examination are debated (see Chapter 1, p. 21) many of the women in the present study were successful in identifying a malignant breast abnormality. Nevertheless, they frequently lacked confidence in their judgment due to their limited knowledge of symptoms particularly those beyond a painful breast lump. This finding can be linked to reports indicating that Government targets to improve awareness of cancer symptoms have yet to be realised (Department of Health, 2006) which may in turn impact on Government objectives for early detection of cancer such as those documented in the NHS Cancer Plan (Department of Health, 2000). Furthermore, some of the women interviewed exhibited avoidance as while they cited a 'knowing' they used distraction as an interim strategy until they could cope with receiving a diagnosis of breast cancer. Participants' illness representations, as illustrated through their cancer schema, most notably those related to morbidity and mortality were central to this behaviour suggesting that increasing public awareness of symptoms may not in itself be sufficient to encourage all women to seek medical advice. Rather, changing perceptions of breast cancer and its treatment should be incorporated into health promotion campaigns. However, this is unlikely to be straightforward as women in the present study were frequently found to avoid medical information that elicited anxiety. This may extend to the detection of symptoms via breast self-examination and represents an area requiring further exploration. What is more, the reluctance of some women to have responsibility for their breast health as demonstrated throughout this research may influence self-examination behaviour in a non-clinical population especially those women who are eligible for mammography screening. The following section focuses on policy developments with regards to information provision and contemplates the

effectiveness of new initiatives in light of the study findings concerning information management.

### **8.3 Information provision and management**

Diagnosis elicited acute stress reactions, including denial, shock, and disbelief. Participants' psychological state combined with the limited timeframe for contemplation was found to influence acceptance of medical opinions and in turn their role in the surgical treatment decision-making process. It is worth re-emphasising that although some women spoke of an active role in surgical decision-making, by definition this was more akin to a shared process and the majority of participants reported passive involvement. Furthermore, while all women interviewed reported a passive role in subsequent treatment decisions this was rarely contested and consciously handing over control to healthcare professionals represented a positive coping strategy. Similarly, during this process and throughout treatment, particularly hospital-based interventions, women managed their access to information and frequently engaged in avoidance, to facilitate coping. This has implications for policy advocating informed and shared decision-making (Department of Health, 2010) as well as for recent initiatives focused around information provision (Department of Health, 2011).

The National Cancer Survivorship Initiative (Department of Health, 2011) is currently testing giving patients a care plan at the end of their primary treatment which includes symptoms of possible recurrence, lifestyle improvements, work and financial concerns and signposting to support groups. The aim is to promote ownership and support survivorship after treatment yet, as illustrated in

this study, the timing of this intervention (after surgery) may prove counter-productive with the stress elicited leading some women to manage this information through avoidance.

Similarly, Fast Access to Cancer Treatment Support (FACTS; Department of Health 2011) is another such programme that has developed across Lancashire and South Cumbria with the aim of raising awareness of patients about oncology emergency. The objective is to enable individuals undergoing chemotherapy to spot the signs and symptoms of life-threatening side-effects through the dissemination of information folders, a FAST alert card and a pre-chemotherapy DVD. The findings of the present study, however, suggest that some women with breast cancer will choose not to view this information given its anxiety provoking properties.

#### **8.4 An altered self**

In line with Goud's (1995) writings, the disruption elicited by a breast cancer diagnosis and treatment regimes challenged participants' notions of the self. Corresponding somewhat to Morse's (1997) model of self development the acute phase of participants' experience rendered little discourse pertaining to self change as these women attempted to cope with the stress elicited by the shock of diagnosis. However, the distress that constituted this period of waiting (until surgery) and behaving differently towards the body suggests a change in women's self-concept, though one which may not be easily articulated. Unlike in many other chronic illnesses, women in the present study reported a lack of symptoms that impacted on everyday life during this time, which may additionally help to explain this finding. Furthermore, the timeframe from

diagnosis to surgery was rarely more than one week leaving little time for acknowledgement of self and identity change. Accordingly, it is proposed that although disruption is at the core of this stage of women's experience that change to the inner self began to emerge with the realisation that they were moving from a state of health to illness.

Full adoption of a transitional identity occurred (Clarke and James, 2003) as participants began to experience the effects brought about by primary treatment with post-operative recovery and frequent engagement in the healthcare system altering these women's previously healthy identity. Women's accounts subsequently reflected the notion of a medicalised self (Tishelman & Sachs, 1998) with their thought processes dominated by medical issues and treatment regimes. During this time these women sought normality and restitution (Frank, 1995), focusing on regaining the self that existed prior to breast cancer in both a physical and psychological sense.

However, in striving for a restored self (Charmaz, 1987) the participants acknowledged that change had occurred though they made attempts to restrict the extent of the altered self. In exploring this issue, the current research has provided support for the distinction between an inner and outer self (e.g. van Wersch, 2001). This is demonstrated through the lack of concordance between women's private feelings and sensations and the outer self enacted through social interaction, habits and women's thought processes regarding the social world. As an example, women's sensed feelings of distress altered their inner self. Yet, they simultaneously engaged in the protective buffering of others by concealing their inner emotions and by behaving as 'normally' as physically possible thereby projecting an unchanged outer self.



Moreover, the role of the body in forming identities and representing the self (Shilling, 1993; Woodward, 2002) adds greater complexity to the application of self theory to breast cancer as the physical impact of breast surgery and adjuvant therapies prevented the participants from re-establishing a healthy identity. Consequently, although these women tried to maintain a predominantly unchanged self, at least in terms of the perceptions of others, the ongoing impact on activities of daily living as a result of breast cancer treatment meant women could do little else but accept an altered self (Charmaz, 2002). Nonetheless, many of the women who participated in the current study hoped that this change would be temporary.

Throughout the year post diagnosis participants' view of the 'self' was often based on interactions and relationships with others (e.g. Charmaz, 1983) which was particularly evident at the mid-way point given the multitude of changes to the body. Importantly, this was rarely linked to actual encounters but rather was the product of women's perceptions of how others would react to their changed body, in terms of breast (including partial loss) and hair loss. This can be linked to Harre's (1998) theory of senses of self, and specifically to the self we are perceived to be by others and which is based on our public expression of self though as noted earlier is complicated by the self we want to project. All participants managed the body, to some degree, through a variety of measures including the use of prostheses, reconstructive surgery, wigs, and clothing. In doing so women hoped to avoid responses that would reinforce their illness identity and the loss of a social feminine identity which would in turn elicit anxiety. Women's confidence during hospital-based treatments was often low and this in itself had a negative impact on interactions with many of the study participants avoiding social encounters with those outside of the immediate

family. While this improved over time women's ongoing management of the body to early follow-up (and potentially beyond) suggests a long-term impact on the outer self. In addition, although identities associated with the former self were often re-established (e.g. employment, housework) and the aim for a fully restored self remained at the heart of the accounts of some women, inner self change was strikingly evident.

These women often rejected a survivor identity (Kaiser, 2008), which can be construed as a social identity via membership in this social category (Gergen, 1991), as they were determined that breast cancer would not alter their way of life despite adjustment to their life perspective. In contrast, twelve months post diagnosis some women had willingly taken on the identity of a breast cancer survivor viewing breast cancer as a platform for action and often planned to undertake activities associated with cancer charities such as the Race for Life.

In accordance with Frank's (1991) notion of illness as a vehicle for self-transformation (as described in Chapter 2, p.50) breast cancer frequently led to a supranormal self (Charmaz, 1987), one that is perceived to be better than that prior to illness. This was illustrated through participants descriptions of an altered personality, which is argued to be integral to the self (Tesser, 2002) and which in the present study was linked to a rediscovered self, that has always been but had gone unrecognised for many years. Similarly, altered priorities and goals, changed behaviours and reformed relationships were integral to these women's new self, though they did not always perceive such change as being linked to the self. Echoing Frank's (1993) concept of an evolving self, one year on from diagnosis women continued to instigate behavioural and life changes, all of which influenced their sense of self and identity.

In summary, the findings from the present study reflect a postmodern view of the self, one that is multifaceted and changes with differing circumstances. However, the research additionally indicates that existing self theory and stage models of the development of a new self (e.g. Morse, 1997) are limited in their applicability to breast cancer. A complex interplay between personal and social identity and the influence of the body in representing the self, which is typically underestimated in theory, have been illustrated throughout this study. Accordingly, participants' use of the body to project an identity or self that was aligned with normality and that they themselves desired yet simultaneously acknowledging change, whether perceived to be temporary due to medicalisation or longitudinal given an altered perspective, constitute unique insights.

### **8.5 Perspectives on embodiment**

Undoubtedly breast cancer brought about a focus of attention on the body and the physical limitations and appearance changes that resulted from treatment regimes (e.g. Leder, 1990; Kelly & Field, 1996). However, contrary to the work of Williams and Bendelow (1998) many participants, particularly those who had undergone a lumpectomy, did not speak of a fragmentation between the body and the self and continued to refer to "my breasts". Conversely, when discussing breast loss women who had undergone mastectomy referred to their breasts as "them" and "the breast" suggesting a disembodied perspective. These women perceived their breasts as external organs that by middle age were no longer functional which is indicative of the notion of the body as a physiological system (Radley, 1996). On the other hand, it could be argued that these perceptions of breasts constituted a separation of breasts from the body

rather than the self. Accordingly, women's sense of embodiment may vary given the meaning ascribed to breasts, the recommended surgical treatment and women's age in relation to childbearing years. The present study has found that the view of breasts as an appendage to a woman's body was reinforced by healthcare professionals particularly through the emphasis on the use of prostheses which Young (1992) argues leads to a view of breasts as replaceable. Women undergoing chemotherapy often displayed signs of disembodiment though this was short-lived, resolving following this treatment. Nonetheless, as suggested by Maclachan (2004) disembodiment may help women to cope with decision-making to change bodily appearance and viewing breasts as outside of the self served as a means of coping and as a self-protection strategy.

Irrespective of the breast surgery conducted all participants considered breast cancer to be separate from the self being something that was alien, had invaded the body and as reported by Lindwall and Bergbom (2009) was threatening to their existence. Moreover, women's desire to "get rid of it" suggests a distancing of breast cancer from the self and echoes the writings of Cassell (1976) who argued that it is disease itself that is objectified. While this has not been found for all illnesses the findings of the current research suggest that this is pertinent to breast cancer though embodiment issues were also evident for some women undergoing particular treatment modalities (e.g. chemotherapy).

The multifaceted nature of the experiences of this study's participants is reflected through application of Franks (1995) four problems of embodiment (Chapter 2, p.55) to breast cancer. On the continuum marked by control at one

extreme and contingency at the other, each end of the spectrum was demonstrated. Women perceived a loss of control over the body throughout the year post diagnosis particularly in relation to having developed breast cancer and the potential for metastases and/or a recurrence as well as physical limitations resultant to treatment. However, they simultaneously spoke of having ultimate control over the body through the power to refuse treatment and via their ongoing management of the body including the impact of treatment side-effects. Similarly, regarding body-relatedness participants were not dissociated from their body in the manner in which Frank suggests as they attended to treatment side-effects and managed bodily appearances. Yet at times, such as that between diagnosis and surgery and immediately post-surgery, women avoided the body, choosing not to look at or touch the body and many participants demonstrated a lack of breast self-examination throughout the year following diagnosis.

Application of the study data to other-relatedness additionally indicates that women may adhere to both extremes of Frank's continuum. Although all participants acknowledged the influence of others (e.g. breast surgeon, partner, and children) in shaping their views of the body and its management (for the sake of others), the body was frequently monadic and separated from loved ones. This was evident when these women looked at, and dressed, the changed body as they typically did so alone. Moreover, while residing in hospital following surgery and for those women undergoing hospital-based chemotherapy, comfort was often found in the knowledge that they were not alone and several women formed supportive friendships from others in the same situation. Accordingly, this is supportive of the "tend-and-befriend" model of stress responses (Taylor et al., 2000) and is in contrast to Frank's suggestion

that the medical system reinforces a separation from other patients. Finally, with regards to the embodiment problem of desire all participants expressed desire through the body as illustrated via their desire for normality in bodily appearance. However, for some women this was situation specific and while at home they chose not to wear an external prosthesis or alter their dress.

Consequently, women may concurrently demonstrate behaviour at each extreme of Frank's continuum of the four body problems throughout the year post diagnosis. Furthermore, the extent to which these embodiment issues emerged varied by situation and time within the illness experience, women's breast cancer schema, perceptions of the body, and social interactions and relationships.

As reviewed in chapter two Frank (1991) relates the problems of embodiment to what he terms ideal body types. The disciplined body-self is theorised to attempt to reassert control through self-regimentation and consequently is marked by dissociation from the monadic body which becomes an "it" to be treated and exhibits a lack of desire. In line with this body-self a focus on and compliance with diagnostic and treatment regimes was noted for all participants and was particularly evident in accounts of the early phase of breast cancer including pre-surgery experiences. Yet, as discussed previously not all participants dissociated from the body or other individuals and the pursuit of medical regimes was perceived to take away women's control over their lives and stimulated a desire for normality. Furthermore, women's experiences of dissociation, control and desire varied according to the prescribed treatment regime which for some women facilitated social interaction. Consequently, while women may conform to some aspects of Frank's description of the disciplined

body women rarely demonstrated all aspects of this body-self. Undergoing a mastectomy and chemotherapy seemed to be most associated with this body type perhaps given the need to cope with breast loss and prolonged hospital-based treatment regimes.

What is more, the participants attempts to reassert normality in their lives included regaining control of the body through managing their appearance with the aim of re-creating a healthy body suggesting that these women additionally concurred to Frank's mirroring body. However, although all participants' accounts reflected this body-self they did so to varying extents with some women seeking reconstructive surgery but others conducting relatively little management of the body and in some situations this group of women chose not to disguise the changed body. It was also apparent that while visual image was central to these women's experiences, survival was ultimately paramount in all cases, influencing acceptance of medical opinions and role in the treatment decision-making process above body image. Contrary to Frank's notions regarding this body type the women who participated in the present study were found to not solely want for themselves but normalised their appearance for the sake of others.

The dyadic dominating body was illustrated through women's anger towards others yet Frank's belief that this occurs due to a loss of desire was not demonstrated rather at its source was the re-negotiation of roles and associated loss of identity within the home (which women desired to return). The issue of dissociation from the body is additionally relevant to this body-self which was not evident for all participants though when present was demonstrated simultaneously with the disciplined and mirroring body-selves. Likewise, the

communicating body-self characterised by accepting a loss of control and the fragile nature of the body was evident in women's accounts particularly one year post diagnosis when they had contemplated existential questions. Women's awareness of the body as a communicating tool and their consequent body management has been previously highlighted though Frank argues is at the core of this body-self. Moreover, Frank states that individuals categorised as a communicative body-self want to relieve the suffering of others and it could be argued that as all women participated in the present research with the aim of helping others that they conform to this body type.

Accordingly, with regards to Shilling's (1993) criticism that it is unclear how Frank's different body types are influenced and chosen the current research findings indicate that when applied to breast cancer, women's sense of self including social aspects of the self are influential. Moreover, these body types do not seem to be chosen as such but emerge as a result of differing changes to the body and consequently the extent to which these body-selves are enacted varies by individual. They may be embodied at different intervals in women's experiences while other body types occur simultaneously both in the short and long-term.

Such criticism can be extended to Frank's (1995) narrative types, which have a basis in self and body theory, as individual women frequently demonstrated narratives of restitution, chaos and quest within their accounts of experiencing breast cancer. Women's wait for normality corresponds to the restitution narrative yet the distress reported during the acute and mid phases often reflected a chaos narrative. Quest narratives were particularly evident during women's final interviews as they contemplated long-term changes to their life



and self as a direct result of breast cancer. Thomas-MacLean (2004b) reported contradictions in women's restitution narrative pertaining to women's acknowledgment of body change but not self change. This was infrequent in the present research and issues regarding the recognition of self change were identified (see chapter 7). Consequently, this research argues that these women did not conform to one narrative type throughout the year following diagnosis but most commonly displayed elements of each, sometimes within the same interview, though to differing extents and for varying lengths of time.

The present study findings also provide some support for the notion of liminality as a link between illness and embodiment, as conceptualised by Little et al. (1998) though concludes that further exploration of this concept is needed. The women interviewed were found to move from a state of perceived health to one of illness which in turn, albeit to differing extents, disrupted women's lives and the relationship between body and self throughout the year following diagnosis. The first stage of the process, acute liminality, began to emerge as women suspected they had breast cancer (as discussed in chapter 5) and receiving the diagnosis subsequently evoked reflection on existential issues and entering into a psychological state marked by stress reactions, disorientation and uncertainty. Participants' cancer schema associating the disease with mortality led to the body becoming a threat to these women's existence and the experience of bodily limitations resultant to treatment regimes further led to an alienation of the self from the body. In accordance with the theory of Little et al. (1998) a full transition back to health and a sense of embodiment did not occur during the data collection period with women remaining between health and illness. Liminality became sustained due to ongoing reminders of breast cancer via the body (e.g. scars, treatment side-effects), managing appearances (e.g. use of

external breast prostheses), ongoing treatment (e.g. Tamoxifen), medical regimes (e.g. hospital-based follow-up) and breast surveillance (whether by women themselves or healthcare professionals). What is more, the loss of normality, ongoing uncertainty and strive to keep breast cancer at the back of the mind further suggests that in the context of breast cancer liminality is experienced in the long-term and potentially throughout survivorship.

As suggested by Little et al. (1998) considerable variation exists in the length of time of the acute liminal phase as while the completion of hospital-based treatments would seem to correspond to the beginning of convalescence and as such sustained liminality, this timing depended on the prescribed treatment regime. Women's financial circumstances additionally influenced their time for reflection and return to normality and as discussed in the previous chapter some women attempted to avoid contemplating existential issues. Furthermore, the finding that women perceived themselves to no longer have breast cancer following surgery, particularly mastectomy, perhaps limits the extent of liminality experienced by some women. The complexity of issues of control identified through the present study, and discussed in relation to Frank's (1995) problems of embodiment, also indicates that sustained liminality should not be defined by acts of control. It is equally noteworthy that the woman experiencing a breast cancer recurrence expected the diagnosis and did not experience the same responses, including those of uncertainty, as other participants. Accordingly it could be questioned whether she had re-entered a state of liminality, or whether she had never ceased to experience liminality. This study has demonstrated that women's evolving experiences of liminality and changed sense of body, embodiment and self required the adoption of multiple coping strategies that were modified throughout the healthcare trajectory.

## **8.6 Coping with breast cancer**

Breast cancer constituted a stressful experience for the women involved in the present study yet in contrast to the premise of Canon's "fight or flight" model (1932 as cited in Ogden, 2007) at the point of diagnosis these women perceived their only option to be fight. As such they engaged in primary treatment with the aim of 'getting rid of it' to ensure the survival of the self and the well-being of loved ones. Furthermore, the participants were found to respond to a multitude of stressors, an evolving process which began even prior to diagnosis with the identification of a breast abnormality. Consequently, the study findings provide some support for the "tend-and-befriend" model (Taylor et al., 2000) as women exhibited a tending response as well as befriending behaviour, drawing on social networks to aid decision-making, manage anxiety and provide support throughout their experience. However, individual circumstances influenced the extent to which the women interviewed displayed both components of the model and these women varied in the drivers underpinning their stress responses.

The multifaceted nature of the experiences of the women in the study sample has additionally been illustrated through their use of multiple coping strategies to manage differing aspects of their experience. In support of prior research participants were found to use avoidance in relation to communication (Donovan-Kicken & Caughlin, 2011) and emotional suppression (Drageset et al., 2009) though this mechanism was a positive strategy used to manage anxiety. This was also evident when these women reflected on existential concerns and faced ongoing uncertainty about their future as they put the negative aspects of breast cancer to the back of their minds in order to facilitate a positive outlook characterised by benefit finding and having hope for the future.

That said, it was not uncommon for participants to experience psychosocial distress including episodes of depression particularly at the mid-point in the year post diagnosis. These women were typically prescribed antidepressants by their GP to manage this aspect of their experience. However, interestingly Emma, whose narrative displayed the most chaos (Frank, 1995), and for whom depression was a prevailing feature did not perceive this drug treatment to be effective. Similarly, Emma found counselling to be traumatic and consequently alternate means of managing this phase of women's experience should be investigated. Numerous women in the present study described considerable physical and psychological benefits from the use of complementary therapies and this may provide one avenue for exploration.

Psychosocial interventions designed to decrease distress and depression in breast cancer patients typically incorporate psychological and pharmacological therapies and report some success (e.g. Akechi et al., 2007) though this combination may warrant revisiting. Investigating reductions in these issues using a longitudinal intervention raises the criticism that as seen in the present study women's emotional reactions to their disease varies naturally over time. Additionally, the passage of time can bring about treatment completion and/or reduction in treatment side-effects and in turn a move towards normality which may in itself reduce women's psychosocial distress. Moreover, the findings from the current study have implications for existing research predicting psychological distress and mood disorders via screening immediately post diagnosis (e.g. Ando et al., 2011) as depression typically became apparent several months following diagnosis subsequent to a period of reflection. This also raises the question of whether women were simply reacting to a stressor, a proposition that was supported by Sarah's account of experiencing a

recurrence, in which she discussed having greater awareness of reactive depression. Accordingly, if managed effectively episodes of reactive depression may not have become a prolonged state and may have decreased the medicalisation of breast cancer.

Women's desire to be positive and find meaning and benefits in their experience has previously been noted in the preceding and current chapters though as reported by McCann and colleagues (2010) the challenges of body and self persisted throughout the year following a breast cancer diagnosis. One year on breast cancer continued to have a presence in women's lives (McCann et al., 2010) through women's body as a permanent reminder and mind via untidy ends including ongoing uncertainty supporting Kaiser's (2008) call for a model of life after breast cancer. However, while some women were found to struggle to regain normality in the longer-term as a result of continuing hospital appointments these follow-up appointments were equally considered to be reassuring. Routine appointments were welcomed by women particularly those who preferred responsibility for their breast health to remain with healthcare professionals and the medical system.

As was advocated in 2002 (Bryan, Holmes, Postlethwaite & Carty, 2002) the breast unit from which participants in the current study were recruited held cost-effective follow-up clinics staffed by specialist breast care nurses. When considering the limitations of such follow-up in relation to detecting recurrence and metastases and the continual high rates of breast cancer diagnoses in the UK, means of easing clinic pressures have been proposed. Routine hospital follow-up being replaced by remote monitoring for patients who are willing to adopt this approach is currently being trialled (Department of Health, 2011).

However, whether this will address women's psychological need for reassurance and support is debatable in light of these study findings.

Above all this research has uncovered that the women who participated in this study experienced breast cancer in different ways depending upon, for example, their medical history, cancer schema, perceptions of the body, social support, and coping strategies. Consequently, not only do models of care need to address women's changing needs throughout the year following diagnosis, and potentially beyond, but psychosocial interventions need to be based in women's experiences.

### **8.7 Reflection on methodology**

The hermeneutic phenomenological approach enabled exploration of women's lived experience of breast cancer throughout the year following diagnosis. The methodology elicited description of women's accounts of their experience as well as interpretation of the meaning women ascribed to these experiences. The longitudinal approach complemented the notion of the hermeneutic circle as the process of questioning and re-examining the text and accordingly the cycle of ideas generated could be explored further during the subsequent interviews. The longitudinal nature of the research proved immensely valuable in revealing changes in women's experiences over time. This approach uncovered transitions such as those from health to illness and women's ongoing wait for normality as well as changes in the self and crucially did so as such transitions occurred. Indeed, the timing of women's interviews often happened during periods of waiting (e.g. prior to or between chemotherapy treatments) and women's accounts suggest that these episodes induced the greatest reflection

on the impact of breast cancer on women's self, identity and emotional well-being.

The longitudinal approach has provided some insight into the timing of issues for individual women throughout the healthcare trajectory highlighting their hopes, fears and coping strategies from diagnosis to early follow-up. The findings obtained provide support for Heidegger's notion that past experiences impact upon the present and future. This was particularly evident in relation to those women who had experienced prior breast disease and/or for whom cancer had featured in their lives previously, influencing responses to diagnosis and surgical treatment decision-making. Reflection on the language recorded in the interview transcripts, as proposed by van Manen (1990) also enabled interpretation of women's sense of embodiment and the meaning of breasts.

In an attempt to encourage production of meaning within the interaction of the interview illness/treatment grids were used. These were completed by the researcher during the interview on the basis of the ongoing discussion with the individual woman. Viewing completion of the grid and being in control of its content helped to alter the dynamic of the interview facilitating researcher-participant interaction through a conversational style of interview. Women were provided with a copy of their grid to review immediately prior to commencing their second and third (where applicable) interviews which assisted the swift development of a rapport. As depicted in the illness/treatment grid of 'Laura' located in Appendix 1, the grids served as a visual reminder of individual women's experience to date and accordingly helped the researcher to ensure coverage of issues that had emerged previously. Moreover, women were able to review and reflect on the present status of these issues and their anticipation of relevant future change. Consequently the grids were a successful

accompaniment to the longitudinal approach and by the final interview allowed women to see a visual representation of their journey. This often led to women commenting on their progression and reflecting on their emotional state and coping at differing time points. The illness/treatments grids were accordingly a valuable tool when conducting multiple interviews over time.

### **8.8 Reflexivity**

As a methodological approach, hermeneutic phenomenology acknowledges that the researcher's knowledge and experiences influence the research process including data collection and analysis. With this in mind, this reflection considers personal and epistemological reflexivity (Willig, 2001) beginning with the position of the researcher and the potential influence on the research process. When embarking upon this research study I was working in both academia teaching psychology and evidence-based practice as well as in the National Health Service in the hospital from which the study sample was drawn leading an evaluation of nursing and surgical roles in cardiothoracic care. I had experience of researching chronic illness and illness management in the context of back pain and in doing so had developed an interest in exploring illness experiences, seeing the value of gaining the perspectives of those who would be affected by policy decisions. I had a broad knowledge of biology and psychology and a working knowledge of the NHS and breast cancer, all of which provided me with the necessary background knowledge and research experience to undertake the study. I had no personal experience with breast cancer.

Discussions with the breast care team led to a realisation that breast cancer was now recognised to be a chronic illness but that few research studies



explored women's experiences over time. Several areas were reflected upon during the early stages of the research study including would participants speak openly to a researcher who had no personal experience of breast cancer, was associated with the site of their healthcare and would women be willing and able to participate in a longitudinal study?

The first interview conducted alleviated any such concerns as 'Linda' displayed an openness and desire to tell her story. This may in part be the result of women reporting viewing the role of researcher as being independent of the Breast Care Unit and their healthcare. This was emphasised by the researcher and may have been further facilitated by participants choosing the location of their interviews. All twenty participants requested being interviewed away from the hospital, preferably in their own homes. As the research progressed possible explanations for this decision emerged including that women had their own pre-conceptions about breast cancer and its treatment and did not wish to add to the deviation from normality elicited by medical regimes and hospital visits. For similar reasons several women stated that they did not want to attend breast cancer support groups and did not wish to speak to other women who had experienced breast cancer, at least while they were undergoing active treatment. Accordingly, in relation to these women, being a researcher with no personal experience of breast cancer was beneficial. It should equally be noted that some women sought support from friends and family who had experienced breast cancer though they too made a conscious decision to not attend a hospital based support group. Maintaining distance from the hospital environment and to an extent breast cancer was evidently important to many of the women interviewed.

Having a working knowledge of cancer and specifically the language of cancer did, however, ensure that when participants used breast cancer terminology as they became immersed in the medical world there was no need to disrupt the flow of their story to ask for clarification of terms. Having no personal experience of breast cancer additionally enabled me to remain open to questions that emerged from studying the phenomenon and allowing text to speak rather than constructing meaning on the basis of personal experience. Nevertheless, it must be acknowledged that much was learned from the first interviews and the process of conducting a large number of interviews enabled the development of lines of questioning as well as my interviewing skills. The longitudinal approach further enabled reflection on emerging interpretations with participants in subsequent interviews and facilitated the development of a trusting relationship. It is this relationship that I believe minimised attrition even when numerous women became unwell due to treatment effects, and enabled me to make informed decisions about returning for subsequent interviews.

My relationship with participants grew over time and while these women shared their highly emotional experiences at time one reliving diagnosis and surgical intervention, the second interviews were frequently the most emotional. At this time point, women reflected on their experiences and mortality and shared thoughts and feelings that they had not previously divulged even to their closest friends and family. This was a humbling experience yet one that brought a sense of responsibility to ensure that these women's stories were accurately represented. The process of engaging with hermeneutic phenomenological research is argued to change the participant and the researcher and this became increasingly evident as the research progressed. Several women

acknowledged the change they experienced as a direct result of the research process:

*'I remember after the second one feeling so much better. I felt like I'd talked about it more than I'd talked about it for ages and I remember thinking that, feeling like I'd had this weight lifted, thinking God I feel loads better for that. I think you try not to tell people who are that close to you how you feel and probably when you sit with your friends they never ask you things like this so they never bring it out'* (Laura; Interview 3; Lines 362-367).

For one participant (Emma) however, the research uncovered the extent of the difficulties being experienced coping with the diagnosis and treatment of breast cancer. During interview two it became apparent that Emma was experiencing significant distress yet was reluctant to seek help from the Breast Care Nurses due to concern that she would be impinging on the time of a busy team. In consultation with Emma I contacted one of the Breast Care Nurses during the interview and facilitated an opportunity for her to acquire additional support. While the outcome was positive for Emma such highly emotional interviews rendered maintenance of hermeneutic alertness (van Manen, 1997) difficult during the interview. Consequently, such stepping back and reflecting on meanings of situations was undertaken following these interviews including during transcription, subsequent interviews (where possible), and data analysis.

One of the most unexpected outcomes of this research was the individual variation in the personal and medical circumstances of the study participants. Several women recruited to the study had experienced prior breast disease, one participant had previously undergone a bilateral mastectomy due to genetic testing while another was experiencing a recurrence. Moreover, three women

initially underwent a lumpectomy yet were later recalled for mastectomy surgery. Such diversity may reflect current trends in the presentation of breast cancer such as the increasing numbers of women presenting with a breast cancer recurrence and the move towards breast-conserving surgery as the primary recommended treatment. Accordingly, while the lack of homogeneity of the sample could be criticised, such variation resulted in the capturing of these emerging experiences.

Reflection is integral to the processes of hermeneutic phenomenology with themes being identified through reflection on what is critical to the experience as well as through the reading of other texts and writing up the study findings. These acts led to greater researcher insight though the huge quantity of data obtained had been unexpected. As such the data often felt overwhelming and transforming it into a readable story that reflected women's longitudinal experiences while managing the diversity of the sample was challenging. Yet, the longitudinal approach and rapport built with the women interviewed enabled the clarity of interpretation to be checked with participants. Similarly, attempts were made to test the intelligibility and meaningfulness of the study findings via presentations to the breast care team and fellow academics.

Finally, returning to the impact of the hermeneutic phenomenological approach on the researcher, this research posed not only an academic challenge but has led to reflection on my own feelings about my body, health and self. At times, particularly during data collection, I found myself becoming increasingly vigilant of conducting screening and healthcare practices. Without doubt this research has had a lasting impact on my life and I am indebted to those women who participated.

## **8.9 Limitations of the study**

The qualitative nature of this study has enabled insight into women's experiences of breast cancer. However, the study is limited to a small sample of participants from one geographical area of the UK and accordingly the research findings lack generalisability reflecting the individual experiences of these women. As a result, this study cannot indicate the prevalence of issues raised such as those pertaining to treatment side-effects. In contrast to relevant existing longitudinal studies the present research focused on breast cancer thereby eliminating limitations associated with amalgamating the experiences of individuals with differing cancer diagnoses. Nevertheless, although none of the women recruited were found to have metastases during the data collection period women varied in their diagnoses with regards to type and stage of breast cancer with some women being found to have lymph node spread. These factors influenced the recommended treatment pathway and in turn women's experiences. That said, the characteristics of the sample were representative of the caseload seen by the symptomatic breast unit. All participants described their ethnic origin as White British though the inclusion of participants from other ethnic backgrounds may have elicited different experiences and alternate meaning ascribed to the issues raised in this study. Likewise, the majority of women who participated in this study reported experiencing stressful life events, including bereavement, divorce, issues with children, and financial difficulties, both in the months prior to diagnosis and throughout the lifespan. Consequently, historical factors are likely to have influenced women's experiences of breast cancer. However, research on stress-tumour pathways indicating that stress may influence tumour growth and the course of disease

(e.g. Antoni et al., 2006) may provide a partial explanation as to the prevalence of such issues in the study sample.

The self-selecting nature of the sample constitutes an additional limitation as recruitment largely relied on the altruism of individual women in terms of returning the required materials to the researcher. The dissemination of recruitment materials by the breast care nurses was deemed to be the least intrusive and ethically appropriate method given the anxiety-provoking nature of attending a symptomatic breast clinic yet the busy nature of the unit meant that accurate response rates could not be established. Accordingly, it is possible that women who did not participate may have reported different experiences.

This study addresses the paucity of longitudinal research exploring women's experiences of breast cancer and allowed transitions, such as from health to illness and women's strive for a return to their former self, to be uncovered. The specific coverage of the year following diagnosis leads to a focus on the acute healthcare trajectory and early follow-up time period. Accordingly, this study cannot provide description or interpretation of women's experiences beyond this point. The recruitment of one woman who was experiencing a recurrence after ten years and another who was diagnosed with breast cancer after having undergone a bilateral prophylactic mastectomy for risk management fifteen years previously enabled some inclusion of aspects relevant to long-term coping as well as reflection on past events though the current diagnosis dominated discussions. The collection of retrospective data is a widespread limitation within breast cancer research and a factor that this study has overcome by conducting a series of interviews during women's active treatment and early follow-up experiences.

Finally, a problem inherent in all qualitative research that of researcher interpretation of data was addressed through member checking at the end of each stage of analysis, facilitated by the multiple interviews conducted with each participant. The ongoing completion of illness/treatment grids further ensured the accurate representation of women's experiences and the issues of relevance to them.

#### **8.10 Directions for future research**

This research has contributed to the gap in the literature by focusing on women's experiences of breast cancer from a longitudinal perspective uncovering issues of relevance to women throughout the healthcare trajectory to early follow-up. This has raised several areas requiring further exploration including those surrounding women's responses to information and explanation. Women's management and often avoidance of information immediately post diagnosis and during the treatment course provokes questions particularly regarding informed shared decision-making and the influence of cognitive dissonance on this process. Furthermore, in light of policy on treatment decision-making and the present study findings regarding preferences for passive involvement, interactions during consultation are an additional area worthy of investigation.

Having previous non-malignant breast disease and/or a family history of breast cancer was noted as influencing treatment decision-making and diagnostic acceptance yet this remains an area lacking exploration. What is more 'Sarah' who was experiencing a recurrence and 'Ellen' who had previously undergone a bilateral mastectomy following genetic screening each provided data that can

be considered a negative case analysis albeit in differing ways. Their experiences suggest that women in such circumstances may have needs that vary from women experiencing breast surgery for the first time. These women exhibited differing insight and expectations, informational needs, preferences for involvement in the treatment decision-making process and an impact on the already changed body and self which requires further examination.

Similarly, few studies have considered the waiting experiences specifically of women with breast cancer and while this research has uncovered this issue during the year following diagnosis, for many women this wait continued at their third and final interview. Consequently, subsequent research could extend data collection beyond this point to explore the full extent of women's wait for normality. This is particularly vital given estimations that approximately 550,000 people are alive in the UK following a breast cancer diagnosis (Maddams et al., 2009).

This research study has demonstrated that women's responses to breast cancer are not dissimilar across differing surgical treatments yet mastectomy dominates the existing literature despite increasing use of breast-conserving surgery. While mastectomy elicited specific themes pertaining to breast loss and the use of external prostheses women who underwent lumpectomy also experienced altered body perceptions and managed the body to disguise breast surgery. Moreover, lumpectomy typically brings the need for multiple non-surgical treatments and with it a different assault on the body. Further exploration of women's experiences in this neglected area utilising a larger sample is required. Only two women in the current study underwent Herceptin treatment, one of whom was a private patient, and this constitutes one area lacking exploration. Likewise, as it is now common practice to prescribe



adjuvant endocrine therapies for five years to reduce the risk of recurrence (Harmer, 2007) women's long-term experiences of Tamoxifen warrant further investigation. The present research identified that many women continued to report side-effects and bodily changes as a direct result of the drug treatment at early follow-up and accordingly longer-term exploration of women's experiences is needed.

### **8.11 Conclusion**

Through a longitudinal exploration adopting a hermeneutic phenomenological approach this research study has revealed the multifaceted experiences of breast cancer of twenty women diagnosed and treated in the North East of England. These women were found to experience breast cancer as a medicalised chronic illness resulting in issues of embodiment and liminality as women made a transition from a healthy identity to a life encompassed by hospital appointments and treatment regimes. Changes to the body disrupted the body-self relationship and while participants typically attempted to restore the inner self, there was often acknowledgment that this was not possible given the multitude of permanent reminders of having been diagnosed with breast cancer. Yet, simultaneously all participants, albeit to differing extents, managed external bodily appearances to maintain the outer self and disguise the signs of illness. Accordingly, the study participants were found to adopt a multitude of coping strategies to manage the body and also the stress, and often elements of grief, elicited by their evolving experience. However, individual variation in women's adaptation to their illness was evident throughout the healthcare trajectory. One year on from diagnosis participants had regained some normality yet acknowledged that they were forever changed by their experience

to date, and an ongoing struggle with uncertainty and treatment side-effects. Finally, this thesis has highlighted that while similarities have been uncovered there is uniqueness in the way in which each woman experiences breast cancer. Consequently, an individual approach to the long-term care of women diagnosed with breast cancer is essential to promote both physical and psychological well-being.

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## **APPENDICES**

APPENDIX 1: Illness/Treatment Grid - 'Laura'

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APPENDIX 6: Semi-structured interview schedule

APPENDIX 7: Swainston, K., Campbell, C. & van Wersch, A. (2007). Life charts mapping disease and treatment trajectory of breast cancer. *Health Psychology Review*, 1: 131.

APPENDIX 8: Letters of ethical approval (Letters identifying the breast care unit and the associated NHS Trust have not been included in order to maintain confidentiality).

APPENDIX 9: Swainston, K., Campbell, C., van Wersch, A. & Durning, P. (2012). Treatment decision-making in breast cancer: A longitudinal exploration of women's experiences. *British Journal of Health Psychology*, 17: 155-170.

APPENDIX 10: Summary of research findings

## **APPENDIX 1**



## ILLNESS/TREATMENT GRID

Participant 07 'Laura'

| Interview | Events   | Decision-making  | Control  | Self   | Comments  |
|-----------|--|--|--|--|---|
| 1         | <p>Found a lump and went to the GP a few weeks later</p> <p>Mammogram and biopsy confirmed breast cancer diagnosis</p> <p>Lumpectomy (20mm)</p> <p>Lymph node sampling 3/11 positive</p> <p>Started chemotherapy</p> | <p>Consultant decided lumpectomy was necessary</p> <p>"It was all very quick, it doesn't give you time to take things in"</p> <p>Initial reaction was to have both breasts removed my initial thing was just to get rid of them both" though the Consultant thought this was too drastic</p> <p>"You do what they say, you do what they think is right"</p> <p>Consultant decided upon the</p> | <p>Everything was discussed but "you've got to put yourself in their hands"</p> <p>"These are the professionals who know what's best for you and that's the route you've got to take"</p> <p>It is your choice but they know what's best for you</p> <p>Loss of control over life while having treatment - "My whole life is surrounded by it and I can't think of anything of else...you count down to the next appointment"</p> <p>In control of breast cancer as no longer have breast cancer the treatment is "making sure I don't</p> | <p>Don't feel ill due to breast cancer but the treatment makes you feel ill</p> <p>"Why me?"</p> <p>"I've lost my zap, a bit of personality... I feel...nervous"</p> <p>Loss of hair means can no longer wear make-up</p> <p>Still feel like woman due to husband and not requiring mastectomy</p> <p>If younger may have felt different</p> | <p>Shock</p> <p>"I heard the word and I don't think I heard anything else after that"</p> <p>Felt like they had made a mistake, were looking at the wrong notes</p> <p>"I still think they've got it wrong because I felt fine"</p> <p>Too much information to take in</p> <p>Frightened of leaving children (death)</p> <p>Side effects from chemotherapy - sickness, taste in mouth</p> |

|   |  |   |   |   |   |
|---|--|---|---|---|---|
|   |  | chemotherapy and the Tamoxifen  | get it again"   |   | "The word cancer makes it real for me"<br><br>"Aiming for the light"  |
| 2 | Chemotherapy ended<br><br>Met with radiologist, planned sessions, ready to start radiotherapy this week<br><br>Various appointments in between to get scar checked | No treatment decisions - these are made for you e.g. about when the radiotherapy starts<br><br>Not making me reassess my life | Difficult to feel in control as backwards and forwards to the hospital. "The chemotherapy was more in control of me"<br><br>"A year out of your life that you have no control over, no say in"<br><br>Put yourself in the hands of doctors and nurses<br><br>In control of what telling the children and in keeping things "normal" for the kids<br><br>"It makes you realise that anything's possible and nobody's immune to anything" | Still hasn't got "zap" back and feels as if has lost some confidence. However, am more hopeful now that it will return as no side effects predicted with the radiotherapy.<br><br>Wanting to look normal for the sake of the children.<br><br>When you lose your hair you "look like you've got cancer"<br><br>Feeling better in self though is difficult as is the treatment that makes you ill not the cancer | Final chemotherapy was better<br><br>Feels "gutted" about starting the radiotherapy as feels so well and yet still having "to go through this"<br><br>It doesn't just happen to other people<br><br>Still asking "why me"<br><br>Next anxious time will be having a mammogram to see whether it has all worked<br><br>At the moment cancer is never far from your mind<br><br>Reassurance at having a |

|   |  |   |  |   |   |
|---|--|---|--|---|---|
|   |  |   |  | <p>After everything you go through the scar is the least of your worries</p> <p>Looking at the scar is comforting - a sign that cancer is no longer there</p> <p>Looking forward to going back to work and being "normal self" again</p>  | <p>number to ring to speak to a breast nurse</p> <p>"You always hear bad stories"</p>   |
| 3 | <p>Completed radiotherapy</p> <p>Started Tamoxifen</p> <p>Hospital check-up with Consultant</p> <p>Back to work on phased return</p> | <p>Decisions regarding radiotherapy and Tamoxifen were made by the Consultant and her team</p> <p>Decision to return to work - felt ready</p> | <p>Before no control but now "it's up to me to get over it"</p> <p>Been in control over "who knows and what information I've given to people...I've kept it all well hidden"</p> <p>Didn't feel in control of radiotherapy as "you're life's not your own, it's literally around hospital appointments"</p> <p>Control over cancer - pleased taking Tamoxifen as it is</p> | <p>Feeling more like "normal self" with return to work, back into a "normal routine"</p> <p>Previously hiding self from others now "I'm not bothered talking about it and I'm not hiding away"</p> <p>Hair loss has had the biggest impact on self and has been the primary reason for the loss of confidence and</p> | <p>Skin sore due to radiotherapy</p> <p>Loss of reassurance once radiotherapy had finished "I thought I'd be so relieved to get it over and I wasn't...that feeling of being on my own"</p> <p>"While you're going up and down there you know it's going away, it's getting better, they're treating it...it so bluntly ends...it's a</p> |

|  |   |  |
|--|---|--|
| "keeping it at bay" and feeling in control of taking the Tamoxifen   | "hiding away"   | safety net"  |
| Control via vigilance over BSE - "you have this side where you know you should be more vigilant but I've got this other side that says I don't ever wanna check them again because I don't wanna know...that silly side wins at the moment because I'm still for check-up's at hospital" | Appreciating things more but "don't think it's changed me" though "can't imagine ever thinking it's over" | "It's time to forget about it and put it behind me"  |
|  | Physical appearance altered - "they're definitely odd to what they were"                                  | Breast cancer means "a year out of your life that's quite horrible but there's a light at the end of it"   |
|  | Need for positive thought   | Life before and after breast cancer - "If there was a bridge I feel as if part of my life is going to be on that side of the bridge and part of it is going to be on this side of the bridge...it's like two separate lives" |

## APPENDIX 1

## PARTICIPANT DETAILS

|   | Pseudonym | Age | Marital status                      | Employment status         | Diagnostic & Treatment Information   | Relevant medical history  | No. of interviews conducted |
|---|-----------|-----|-------------------------------------|---------------------------|--|---|-----------------------------|
| 1 | Linda     | 66  | Married<br>Previously widowed       | Retired                   | 2 DCIS's identified; Mastectomy; Axillary sampling - node negative   |   | 3                           |
| 2 | Margaret  | 61  | Married                             | Full-time                 | Lumpectomy; Axillary sampling of 9 nodes - node negative; Radiotherapy                                     | Previous lump in breast in 2005 - identified as fatty deposit, no treatment required                        | 3                           |
| 3 | Ellen     | 55  | Married<br>Separated by interview 3 | Full-time                 | Removal of all remaining breast tissue; Axillary sampling - node negative; Tamoxifen                       | Previous bilateral mastectomy conducted following genetic testing which identified participant as high risk | 3                           |
| 4 | Rose      | 51  | Married                             | Full-time<br>Own business | Mastectomy; Axillary sampling - node positive; Chemotherapy; Herceptin                                     | 8 years ago cyst in right breast  | 3                           |
| 5 | Louise    | 57  | Divorced                            | Full-time                 | G3 ductal cancer; Lumpectomy; Axillary sampling - 3/5 node positive; Chemotherapy; Radiotherapy; Tamoxifen |   | 3                           |
| 6 | Fiona     | 68  | Married                             | Retired                   | Lumpectomy; Axillary sampling - node negative; Radiotherapy;   | Previous diagnosis of MS  | 2                           |

|    |           |    |                                       |           |  |  |   |
|----|-----------|----|---------------------------------------|-----------|--|--|---|
|    |           |    |                                       |           | Tamoxifen  |  |   |
| 7  | Laura     | 41 | Married                               | Full-time | Lumpectomy; Axillary sampling - 3/11 node active; Chemotherapy; Radiotherapy; Tamoxifen                                      |  | 3 |
| 8  | Susan     | 58 | Widow                                 | Full-time | Mastectomy; Axillary sampling - 2/6 node positive; Chemotherapy; Radiotherapy; Tamoxifen                                     | 2003 blocked milk ducts<br>2005 infections in breast               | 3 |
| 9  | Amanda    | 46 | Married                               | Full-time | Lumpectomy followed by mastectomy; Axillary sampling - node positive; Chemotherapy; Radiotherapy; Tamoxifen; Ovaries ablated | Previous lump in breast 20 years ago - identified as fatty deposit | 3 |
| 10 | Janet     | 49 | Long-term partner<br>Previous divorce | Full-time | Lumpectomy; Axillary sampling - node negative; Chemotherapy; Radiotherapy  | History of cysts in breast tissue requiring drainage               | 3 |
| 11 | Elizabeth | 57 | Divorced                              | Full-time | G2 lobular cancer; Lumpectomy; Axillary sampling of 4 nodes - node negative; Radiotherapy; Tamoxifen                         |  | 2 |
| 12 | Gillian   | 43 | Married                               | Full-time | Lumpectomy followed by mastectomy; Axillary sampling of 9 nodes - node negative; Tamoxifen                                   |  | 3 |
| 13 | Pauline   | 67 | Married                               | Retired   | G2 - lobular and ductal cancer; Mastectomy; Axillary sampling of 5 nodes - node negative; Tamoxifen                          |  | 3 |
| 14 | Lily      | 67 | Widow                                 | Retired   | G1 cancer; Mastectomy; Axillary  |  | 2 |

|    |       |    |                             |           |  |  |   |
|----|-------|----|-----------------------------|-----------|--|--|---|
|    |       |    |                             |           | sampling - 3/8 node positive;<br>Tamoxifen   |  |   |
| 15 | Maria | 58 | Married                     | Housewife | Mastectomy; Axillary sampling - 5/12 node positive;<br>Chemotherapy; Radiotherapy; Herceptin                       | Removal of cysts in breast tissue 6 years prior to breast cancer diagnosis   | 3 |
| 16 | Joan  | 48 | Married                     | Full-time | Ductal cancer; Lumpectomy; Axillary sampling - 20/26 node positive; Axillary clearance; Chemotherapy; Radiotherapy |  | 3 |
| 17 | Sarah | 49 | Widow                       | Full-time | Two G2 tumours; Bilateral mastectomy; Axillary sampling - 4/11 node positive; Chemotherapy; Radiotherapy           | Diagnosis of breast cancer 11 years prior to current diagnosis. Lumpectomy, chemotherapy and radiotherapy had been undertaken. | 2 |
| 18 | Emma  | 49 | Divorced                    | Full-time | Mastectomy; Axillary sampling - 1/9 node positive; Chemotherapy; Radiotherapy; Tamoxifen                           |  | 3 |
| 19 | Jenny | 54 | Widowed<br>Previous divorce | Full-time | Mastectomy; Axillary sampling - node negative; Tamoxifen   |  | 3 |
| 20 | Mary  | 45 | Married                     | Full-time | Lumpectomy followed by mastectomy; Axillary sampling - 1 node positive; Chemotherapy; Radiotherapy                 |  | 3 |



## **APPENDIX 10**

Version 2

8<sup>th</sup> July 2005

## **PATIENT INFORMATION SHEET**

### **Study Title**

An exploration of women's experiences of breast cancer throughout the healthcare trajectory.

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Please ask the researcher (Katherine Swainston) if there is anything you do not understand or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

### **Background**

Identity and a sense of embodiment become significant when at a time of illness the body becomes the focus of attention. So far no research has asked women with breast cancer to discuss their experiences of identity and embodiment issues throughout the health care period. These issues may influence a woman's perception of control over her illness and her treatment and in turn impact upon decision-making and treatment preferences.

### **What is the purpose of the study?**

This study wants to find out about the experiences of identity and embodiment issues from the perspective of women with breast cancer. In particular the research aims to look at the implications of this for perceived control and decision-making.

### **Why have I been chosen?**

You have been chosen because you have breast cancer. Twenty women attending this clinic will be asked to be part of the study.

### **Do I have to take part?**

It is up to you to decide whether to take part or not. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you do decide to take part, you are free to withdraw at any time and without giving a reason. This will not affect the standard of care you will receive. Your doctor will not be upset if you decide not to take part.

### **What will happen to me if I take part?**

I would like to interview you to discuss your experience of having breast cancer approximately every six weeks for up to 12 months. As part of the interview I would like you to help me to complete an illness/treatment grid to chart these experiences including the decisions that you come to about your treatment. Each interview will be audio tape-recorded and will take from 30 minutes up to one hour, though can finish whenever you wish.

I would also like you to write down your experiences in between each interview in a diary provided by the researcher. This will be as and when you want and some months you may not want to write anything. This research does not require you to restrict what you eat or do.

**What are the possible disadvantages and risks of taking part?**

There are no disadvantages in taking part and there are no risks involved.

**What are the possible benefits of taking part?**

It is hoped that the study will help health care professionals gain a better understanding of identity and breast cancer and the implications of these for perceived control and decision-making. This may help improve communications with women with breast cancer and could be used to improve patient information leaflets.

**What if new information becomes available?**

You will be told if important new information about this study becomes available which might affect your willingness to continue taking part. If at any time the researcher considers it in your best interest they will withdraw you from the study. They will explain the reasons and arrange for your care to continue.

**What happens when the research study stops?**

You will continue just the same as you did before and during the study.

**What if something goes wrong?**

It is very unlikely that you will be harmed by taking part in this study. Thinking about your breast cancer may cause you to become upset. The researcher Katherine Swainston is aware that this may be difficult for you and you can stop at any time if you do not want to continue. A counsellor is available if you do become upset and want to talk to someone about this.

You also need to know that there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it. Any published report of the research will not identify you. Your GP will normally be informed that you are taking part. If this is a problem for you, you should discuss it with the study researcher Katherine Swainston.

**What will happen to the results of the study?**

I hope to share the results of this study with other doctors and health care professionals by presenting the findings at meetings and by publishing research papers that describe the study and what I found. I will also provide you with a summary of the results.

**Who is organising and funding the research?**

The research is being conducted by Katherine Swainston, a researcher at the University of Teesside. Your doctor will not be paid for including you in this study.

**Who has approved the study?**

The University of Teesside ethics committee, the Research Approval Board at the NHS Trust and the Local Research Ethics Committee have approved this study.

**Contact for Further Information**

Katherine Swainston 01642 738013  
07774091950

Thank you for reading this information sheet. You can let me know that you are willing to take part in the study by signing the consent form that is attached and returning it to the researcher in the envelope provided. If you do decide to take part you will be given a copy of the signed consent form to keep.

## **APPENDIX 10**

**Version 2**  
**08.07.05**

## **CONSENT FORM**

Title: An exploration of women's experiences of breast cancer throughout the healthcare trajectory.

Researcher: Katherine Swainston

Please initial box

1. I confirm that I have read and understood the information sheet dated 8<sup>th</sup> July 2005 (version 2) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal right being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the hospital and The University of Teesside or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I give permission for the researcher to audio tape-record all interviews that I give.
5. I agree to take part in the above study.

| Name of Participant | Date | Signature |
|---------------------|------|-----------|
|---------------------|------|-----------|

### **Participant contact details**

| Researcher | Date | Signature |
|------------|------|-----------|
|------------|------|-----------|

1 for participant; 1 for researcher; 1 copy for GP

## **APPENDIX 10**

## **Version 1**

**16.02.05**

### **DEBRIEF**

Title: An exploration of women's experiences of breast cancer throughout the healthcare trajectory.

Researcher: Katherine Swainston

The research in which you have participated aimed to explore experiences of breast cancer, embodiment and identity in relation to women's perceptions of control and decision-making throughout their treatment course.

I would like to emphasise that all information provided by yourself will be treated with strict confidentiality and under no circumstances will your name or any identifying characteristics be included in any subsequent reports or publications. If you have any further questions about this study I would be more than happy to assist and can be contacted via e-mail on [K.Swainston@tees.ac.uk](mailto:K.Swainston@tees.ac.uk) or by telephone on 01642 738013 (University) or 07774091950 (mobile).

The organisations listed below offer a confidential service and provide advice and support for women with breast cancer.

- The Breast Cancer Support Group (Middlesbrough) can be contacted on 01642 285418/ 01642 535935. This group meets regularly at the James Cook University Hospital, Middlesbrough.
- The Breast Cancer Care Helpline is available Monday - Friday 9am-5pm and Saturday 9am-2pm: 0808 800 6000
- Cancer BACUP: Freephone 0808 800 1234

Thank you for your participation



## **APPENDIX 10**

## **SEMI-STRUCTURED INTERVIEW SCHEDULE**

### Initial Interview

The initial interview will revolve around questions such as those detailed below.

- What has been explained to you about your breast cancer?
- How did you feel about being diagnosed?
- What impact did this have on you?
- What impact did this have on your family and friends?
- What do you expect to happen now?

### Subsequent Interviews

To be guided by individual women's experiences and issues that emerge throughout the data collection process.

- What has been your experience of having breast cancer over the last six months?
- What does it mean to you at this moment in time to be a woman with breast cancer?
- How would you describe yourself as a person at this moment in time?
- What decisions have been made within the last six months?
- How did you come to that decision?
- How would you describe the treatment decision-making process?
- How do you think this experience will affect you over the next six months/the rest of your life?

## **APPENDIX 10**

**Life charts mapping disease and treatment trajectory of breast cancer**

K. Swainston, C. Campbell, A. van Wersch; University of Teesside, Middlesbrough, United Kingdom

Disease and treatment trajectory tend to differ between patients. Is this because people vary in their biopsychosocial responses to a condition? Or are different treatment decisions made on the basis of certain unknown factors? This study aims to examine this process of variation in more detail with respect to breast cancer. Kane (1983) recommended the use of longitudinal studies in order to understand how social circumstances and health care interventions could effect psychological outcome variables over time. Previous longitudinal studies in breast cancer have mainly studied distress (Manne et al., 2005; Wade et al., 2005) or quality of life (e.g. Hurria et al., 2006; Segrin, 2005). This research will unravel the individual process of control and decision making in the trajectory of health care in relation to patients' perceptions of their illness, their embodiment and their identity. Twenty patients from a breast clinic of a hospital in the North East of England were interviewed at a regular three-months interval during the course of one year. In collaboration with the patients, illness/treatment grids were completed, which resulted in the charting of the treatment and decision-making processes. Three case studies will be presented, discussing and visually representing (via adapted life charts) the experiences of patients and highlighting the issues which have emerged during data analysis.

**Keywords:** *Breast cancer, life charts, trajectory*

## **APPENDIX 10**

12<sup>th</sup> May 2005

Dr Carol Campbell

Dear Carol Campbell

Project title: **An exploration of experiences of breast cancer, embodiment and identity issues in relation to women's perceptions of control and decision-making in their trajectory of health care**

Katherine Swainston

The above proposal has received ethical clearance and the project may proceed.

Yours sincerely



Jfbfc Bunton  
' Chair  
Research Ethics Committee  
School of Social Sciences and Law



INVESTOR IN PEOPLE

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## **APPENDIX 10**

## Treatment decision making in breast cancer: A longitudinal exploration of women's experiences

Katherine Swainston<sup>1\*</sup>, Carol Campbell<sup>2</sup>, Anna van Wersch<sup>1</sup>  
and Patricia Durning<sup>3</sup>

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College of Arts & Sciences, Zayed University, Abu Dhabi, United Arab  
Emirates The James Cook University Hospital, Middlesbrough, UK

**Objectives.** To explore the lived experience of breast cancer in relation to the treatment decision-making process over time.

**Design.** Adopting a hermeneutic phenomenological approach, semi-structured inter-views were undertaken at three points in time during the year following diagnosis.

**Methods.** After ethical approval had been obtained, 20 women who were recently diagnosed with breast cancer were recruited from a Symptomatic Breast Cancer Unit in the North East of England.

**Results.** Four themes emerged: role in the treatment decision-making process; acceptance of medical opinions; getting rid of it; and cancer schemas. The majority of women reported a passive role in the surgical treatment decision-making process and all women did so in relation to subsequent treatment decisions. However, women adopted this role consciously and consequently were not disengaged from the process but maintained a sense of ownership and control over their health. The women did not describe experiencing decisional regret at any point in the year following diagnosis and rarely revisited the decisions made, only doing so in a positive manner. Trust in the abilities and experience of healthcare professionals and maximizing chances of survival were cited as reasons for not having had greater involvement.



Despite being given information about treatment options, many women made the decision not to attend to this information perceiving this to be anxiety provoking.

**Conclusions.** The findings from this study suggest a need for eliciting more specific psycho-social interactions in the treatment decision-making process in order to identify ways in which women can be supported throughout their experience.

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8287.2011.02028.x

Research concerning the involvement of women with breast cancer in treatment decisions gained popularity in the 1980s. The high proportion of mastectomies being undertaken led to concerns about surgical over-treatment and a lack of patient involvement in treatment decisions. Randomized controlled trials conducted at the time indicated that less invasive treatment options such as lumpectomy with radiotherapy yielded comparable outcomes to radical mastectomy (e.g., Fisher *et al.*, 2002). Consequently, full disclosure of surgical treatment options for breast cancer became widely advocated. However, such clinical and public health policies were developed despite a lack of rigorous empirical data about the decision-making process (Katz & Hawley, 2007).

Recent research suggests that the treatment decision-making process is complex and one which many women with breast cancer find difficult (e.g., Polacek, Ramos, & Ferrer, 2007). Decisions are typically made in a short period of time, often during the first meeting with the general surgeon, in order that surgical treatment can be undertaken as soon as possible. Other treatment decisions, for example, regarding chemotherapy, radiotherapy, and adjuvant drug treatments are also made within the first few weeks after diagnosis.

There is currently a substantial body of quantitative research on breast cancer treatment decision making. This encompasses genetic testing (e.g., Jacobsen, Valdimars-dottier, Brown, & Offit, 1997) and breast cancer screening (e.g., Rakowski *et al.*, 1992), the influence of the surgeon's characteristics in the decision-making process (e.g., Hawley *et al.*, 2007) and the development and evaluation of decisional aids in facilitating this process (e.g., Hack *et al.*, 2003; Whelan *et al.*, 2004). Patient involvement in breast cancer treatment decision making, particularly regarding surgical treatments options, also dominates this field. One study by Vogel, Helmes, and Hasenburger (2008) reported that 40% of patients preferred to delegate treatment decision making to the clinician, while 29% wanted collaboration. Surprisingly, only 31% wanted to select their own treatment. Such results suggest that while some patients prefer a dominant role in surgical treatment decision making, others may prefer the surgeon to be more active in this process. However, having autonomy within the context of a traditionally authoritarian model of healthcare may be difficult for women who are not accustomed or prepared for this process (Thomas-MacLean, 2004).

One prospective cohort study (Temple *et al.*, 2006) aimed to describe the proportion of women anticipating having breast-conserving surgery (BCS) versus modified radical mastectomy (MRM). Furthermore, this research aimed to explore factors involved in making these treatment decisions and the degree of control felt in relation to treatment decisions. Of 157 participants, 28.7%

anticipated having (MRM) compared to 71.3% who anticipated having BCS. Women cited doctors' advice and possibility of complete cure as the predominant factors in aiding the decision-making process with the majority of women (60%) reporting that they had participated in treatment decisions to the extent they desired. Multiple regression analysis found that the type of planned surgery was predicted by surgeon, concerns about cancer recurrence, contribution of the doctor, self-efficacy, and the importance of breasts to sexuality. However, only 13.6% of women in this study felt that they had received their preferred amount of information with which to make these treatment decisions. Similarly, a large-scale study of women diagnosed with breast cancer also found that the majority of women surveyed had little knowledge about the recurrence and survival associated with the different surgical options available to them (Fagerlin *et al.*, 2006).

Reaching informed decisions about breast cancer surgical treatments can be difficult for many women though Fallowfield, Hall, Maguire, Baum, and A'Hern (1994) found no evidence that giving women the choice of mastectomy or lumpectomy in itself prevented psychiatric morbidity. However, 'consulting style, in particular offering satisfactory information about treatment options was crucial to long-term adjustment' (p. 203). Likewise, an association between satisfaction in surgical choice and achieving the preferred amount of involvement in the decision-making process irrespective of treatment received suggests that the decision-making process may be as important as the decisions themselves (Sabo, St-Jaques, & Rayson, 2007). Research findings further indicated that women actively involved in surgical treatment decision-making report significantly higher quality of life than women who indicated passive involvement and that as women progressed along their breast cancer trajectory they tended towards a stronger preference for active and collaborative involvement in their medical care (Hack, Degner, Watson, & Sinha, 2006).

Such quantitative research provides a valuable insight into the level of women's involvement in treatment decision making and to an extent the factors influencing these decisions. However, an in-depth understanding of women's experiences of the decision-making process is essential in order to improve the support provided by healthcare professionals afforded to women who receive a diagnosis of breast cancer. To date, few studies have addressed women's experiences of breast cancer decision making from a qualitative perspective and those that have done so highlight the need for extensive further research. One such study (Halkett, Arbon, Scutter, & Borg, 2007) reported that women described being required to make many decisions following diagnosis each of which elicited an emotional challenge and that women felt a need to prepare for the decisions to be made. Furthermore, the

authors stated that women may feel a loss of control over their situation and may struggle to regain that sense of control. Participants in the Halkett study reflected on the importance of family and friends in the decision-making experience, and often felt that treatment decisions should be shared with others. Furthermore, there was a feeling that the decisions, once made, had an ongoing effect on their lives.

Similarly, in the qualitative exploration by Thomas-MacLean (2004) several women described experiencing difficulties when making choices about surgery and adjuvant treatments. The study further reported that these decisions were questioned long after all treatments had been completed. Seale (2005) who performed a quantitative and qualitative comparative content analysis of portrayals of treatment decision making on the most popular UK breast cancer website identified several accounts describing handing over decision-making control willingly. The difficulty and stress experienced in the decision-making process and consideration of family obligations were also identified via data analysis.

The paucity of research exploring women's experiences of breast cancer decision making, and particularly those treatment decisions that extend beyond initial surgery is to be addressed by this paper. The study objective was therefore to explore the lived experience of breast cancer in relation to the treatment decision-making process over time, specifically, throughout the year following diagnosis.

## **Method**

### ***Design***

A qualitative hermeneutic phenomenological approach utilizing semi-structured inter-interviews was employed in order to elicit meaning of the lived experience of breast cancer and thus enable exploration of issues around treatment decision making. Phenomenology's 'goal is to describe human experience as it is lived' (Merleau-Ponty, in Beck, 1994, p. 500) and thus provides a theoretical orientation through which an increased understanding of the meaning of breast cancer can be attained. Specifically, hermeneutic phenomenology is viewed as both descriptive and interpretive describing individuals' accounts of their lived experience as well as interpreting the meaning that individuals attribute to these experiences (van Manen, 1990). Based on the metaphor of the hermeneutic circle (Heidegger, 1996), this approach suggests that experiences can be considered as a whole and in parts, and that everything is interrelated.

Sixteen participants were interviewed three times in the 12 months subsequent to their breast cancer diagnosis and a further four women were interviewed twice within a 7-month time period. Data saturation occurred

during interview 2 for three of these women and one participant was non-contactable by the time of the third interview.

Initial interviews were conducted within 1–5 months following diagnosis with the mean time between diagnosis and interview 1 being 2 months (an average of 1 month post operative). The range time between diagnosis and interview 2 was 4–10 months with a mean time since diagnosis of 6.5 months. Interview 3 was undertaken within 10–17 months with an average of 13 months elapsing since the point of diagnosis. The spacing of individual women's interviews was dependent upon the availability of both participants and the interviewer. Interviews lasted between 35 and 90 min and were conducted in participants' homes by the first author.

### ***Participants***

Recruitment took place at a symptomatic breast cancer unit in the North East of England. All women attending the unit between April and December in 2006 who were diagnosed with breast cancer, were aged 18–75 years and were able to give informed consent were approached by the breast care nurses to participate where possible.

Twenty women who met the inclusion criteria and were willing to participate returned a signed consent form including their contact details to the first researcher within the recruitment timeframe. Given the busy nature of the clinic, it was not possible for the breast care nurses to monitor exact response rates. However, the clinic receives over 3,000 new referrals each year, of which approximately 200 women are diagnosed with breast cancer. The number of women diagnosed is highly variable week to week typically ranging from 2–5 women per week. During the first half of the recruitment phase of this study, the average number of women being diagnosed was noted as being fewer than average. Recruitment was also postponed whenever staffing levels in breast clinic were low since no time was available for the breast care nurses to assist with the project. Of those women who did agree to participate in this research, one woman was experiencing a cancer recurrence and for another the breast cancer diagnosis was given 10 years after a high-risk genetic assessment and bilateral prophylactic mastectomy. At the time of the first interview, all women had undergone surgery (either lumpectomy [N = 7], mastectomy [N = 12] or removal of remaining breast tissue [N = 1]) and were receiving additional treatment(s) such as chemotherapy, radiotherapy, pharmacotherapy, or combinations of these treatments. Two women initially underwent a lumpectomy and returned shortly thereafter for a mastectomy. No women in this sample underwent immediate breast reconstruction. During the study, timeframe-one women completed breast reconstructive surgery (9 months post diagnosis) and a further three women described themselves as actively pursuing

this course of action during the third interview.

The age range was from 41 to 67 years of age (mean age of 54 years). Thirteen participants were married at the time of the first interview, four women were recently divorced, and three were widowed. Nineteen participants had children of which eight participants had children living with them at home. Fifteen participants were working full-time at the time of diagnosis, a further four participants were retired and one participant described herself as a housewife.

### ***Materials***

The study materials comprised a study information sheet, a consent form, a debrief sheet, and a stamped addressed envelope. A semi-structured interview schedule and an illness/treatment grid were also constructed. Initial interviews began by asking women 'Can you describe how you came to be at the breast clinic?' Women were prompted to report their stories of breast cancer from the point of identification to the present day including any previous history of breast disease. Subsequent questions focused around participants' experiences and perceptions of diagnosis and treatment decision making and the impact of these processes on their lives. Interviews 2 and 3 began with a review of the previous interview discussions, enabling the first researcher to check the accuracy of the data and thus confirm the emergence of themes. Participants were asked to express their experience of breast cancer over the previous few months and were asked questions such as 'How would you describe yourself at this moment in time?' Questions focused around the emerging themes for each individual and in particular issues relating to decision making and perceived control with the use of questions including 'How would you describe the control you feel in relation to breast cancer'. During the course of each interview, an illness/treatment grid was completed by the researcher in conjunction with the participant summarizing the key experiences and perceptions revealed. Additional key issues were entered into the grid at the time of transcription under the headings: events, decision making, control, self, and comments. Participants were given a copy of their grid to review at the start of each interview and this was used as an *aide memoire* by both parties throughout the interview. This served to engender a sense of control by participants over the interview process and provided a visual representation of women's progress throughout the healthcare trajectory.

### ***Procedure***

Following University research ethics approval, local hospital research approval as well as approval from the local branch of the National Research Ethics

Service, the first researcher supplied study information sheets and consent forms with stamped addressed envelopes to the symptomatic breast cancer unit. Upon receipt of signed consent forms, the first researcher contacted participants to arrange a suitable time for interview. Written consent was obtained prior to commencement of each interview, all of which were conducted in participants' homes at their request. All interviews were tape recorded and transcribed verbatim. Participants were given a debrief sheet including details of local breast cancer support groups and a variety of support services available.

### ***Data analysis***

Data were analysed in accordance with van Manen's (1990) approach to analysis in order to identify the meaning of women's lived experiences of treatment decision making following a diagnosis of breast cancer. Engaging in a 'free act of seeing', the method aims not to apply coding as in other methods of qualitative data analysis but to elicit meaning hermeneutically (Langdridge, 2007). Obtaining a balance between the whole, the general meaning, and the parts, what is specific to the individual began with the sententious approach. This involved reading and re-reading individual transcripts and identifying sentences or phrases that were deemed to be representative of the experience as a whole. The highlighting approach subsequently identified emerging themes and helped to foster an understanding of a number of elements of the phenomenon. This process was applied to the data in four stages: analysis of all first interviews (N = 20); analysis of all second interviews (N = 20); analysis of all third interviews (N = 16); and finally an overall analysis of the interviews (N = 56). Each woman was assigned a pseudonym.

### **Findings**

Four themes emerged from the data: role in the treatment decision-making process; acceptance of medical opinions; 'Getting rid of it'; and cancer schemas. Each theme was found to be interrelated with the other themes and represented women's longitudinal experiences of the treatment decision-making process.

#### ***Theme 1: Role in the treatment decision-making process***

When asked to reflect upon the treatment decision-making process, during the first interview, women who had a history of previous breast disease and/or, like Jenny, a family history of breast cancer, considered themselves to have had an active role in surgical decision making.

'The doctor said "well we'll do a lumpectomy" and it was my decision to say no and she (doctor) came out of theatre and said "right what are we doing?" and I said "take it off" (Jenny).

Sarah, who was experiencing a recurrence, described having made the decision to have a mastectomy prior to being given the diagnosis for the second time.

'There was no sense of shock, it was almost as if I sensed that this would happen, looking at my family history at some stage I knew I would have a re-occurrence. When you've gone through a process for eleven years you actually see an end and the only way I can describe it is it's almost like running a marathon, you hand the baton over and somebody gives you it back and says go and run it again but not the same journey, we'll give you a different route. So, it's almost as if I don't want to do it again eleven years on. I've spent a lot of time reflecting on my life and what I would do so the decision was made prior to me going'.

Furthermore, for Sarah perceiving an active role engendered a sense of control over her experience.

'Being in control, driving decisions has made it a lot easier for me this time around'.

The remaining participants in the sample revealed having had a passive role in surgical treatment decision making. During the first interview Elizabeth recalled:

'I think it was the doctor that made the decision (to have a mastectomy) because when I had the biopsy I had to wait for the results to come back so I think they made the decision to have that'.

Similarly, Fiona commented:

'Well the doctor said it'll be a lumpectomy, it won't need to be a mastectomy because it's only small. They said what we do is we take the lump away and some of the lymph glands under your arm and they said you might have to come back if we find something in the lymph glands, come back for more treatment. I said whatever you think needs to be done do it' (Fiona).

None of the 20 women interviewed reported an active role in decision making with regards to other treatments (chemotherapy, radiotherapy, and adjuvant drug treatments). Participants often cited the multidisciplinary team as making all non-surgical treatment decisions. This is illustrated in the following two



comments:

'I think they have a multi-disciplinary team and I think they discussed the radiotherapy in the team meeting and they obviously considered that to be the best plan' (Susan).

'The breast nurse told me the results and told me what the team had suggested and because it hadn't spread they said I didn't need chemo' (Janet).

Having a passive role in the treatment decision-making process was described by women as a positive aspect of their experience. The shock of diagnosis and the need to make decisions quickly in order to receive timely treatment were cited by women as reasons for not engaging further.

'I just said to her "I'll do whatever you think" because I was just that shocked I didn't know what to say. I just said to her "whatever you think is best just do because you know what you're doing"' (Emma).

The level of involvement in the surgical treatment decision-making process therefore differed among participants given their medical history. Nevertheless, decisions regarding additional treatments were led by the various medical professionals involved in women's care. Taking a passive role in this capacity was accepted willingly and was not automatically perceived by women to be associated with a loss of control. Feeling able to ask questions and being ultimately responsible for acting upon the decisions made (e.g., attending appointments and adhering to treatment regimes) fostered a feeling of having ownership over the treatment decision-making process.

'I did feel that if I wanted to question or argue I could have. I chose not to because I felt that decisions were made by a team of professionals, not just one person . . . but it was my decision to go through with the surgery and I decide whether to take the Tamoxifen each day' (Pauline).

Positivity regarding treatment decision making was maintained throughout the year following diagnosis with women continuing to state that all treatment decisions, including surgical decisions, had been appropriate. During interview 3, 1 year following diagnosis, Linda commented:

'If I had to do it again I would have done exactly the same. I cannot fault the doctor at all, in fact I think he's magic and if it was to come again I would want to go with him'.

Many women were so comfortable with the choices made that they did not feel the need to revisit the decision-making process during subsequent interviews. Women continued to rationalize their role in the treatment decision-making process and the choices made in relation to their acceptance of and trust in medical opinions.

### ***Theme 2: Acceptance of medical opinions***

Regardless of the role in treatment decision making or previous medical history acceptance of and trust in medical opinions was unwavering for all participants throughout the healthcare trajectory. This is reflected in the following quotation:

'They had my best interests at heart and I had to put my trust in the team to do their best, I trusted them to do the best possible job they could do' (Gillian).

Likewise, in interview 1 Laura commented:

'You've got to put yourself in their hands. They are the professionals who know what's best for you and that's the route you've got to take'.

This trust in the abilities of the breast care team was described by women as enabling them to take a passive role in treatment decision making and avoid additional anxiety. Furthermore, women perceived the active role of the medical team as facilitating a smooth progression through the initial post-diagnosis period.

'It (treatment decision-making) was taken out of my hands but because of that it has all really flowed, everything's gone according to plan and according to timescales' (Amanda).

For two participants initial medical opinions that a lumpectomy would be sufficient were revised following surgery and thus a mastectomy was subsequently required. However, rather than losing trust and confidence in the medical team, Amanda refers to the expertise of her surgeon.

'I was devastated because I was just getting used to the smiley scar underneath my boob which was very, very neat and I must admit she's fantastic at the job she does. Just shock and disbelief but I felt lucky to be truthful with you. I do feel lucky because if I hadn't gone and had the lumpectomy and if she hadn't taken the extra bit then who knows'?

Trust in the knowledge, expertise, and abilities of medical staff was reflected upon by all women in this study throughout the year following diagnosis. Once

treatment had been completed, this took on the role of acceptance of opinions relating to wellness and trust that the breast care nurses would identify a recurrence.

'They checked both, even this one you know and even though I'm checking I'm pleased they're checking because I might miss it. A full examination and it makes me feel at ease because if there's anything they'll pick it up, quicker than me. I can't feel anything but they might' (Kath).

### ***Theme 3. 'Getting rid of it***

During the first interviews, women spoke at length about the treatment decision-making process and in subsequent interviews reflected on the decisions they both did and did not make. Having the diseased tissue removed was, however, described by all participants as their main concern.

'My priority was to remove the problem, the cancer' (Sarah).

For several participants, their initial reaction to the diagnosis involved a desire to have the cancerous breast removed. The underlying reason for this was a belief that a mastectomy would increase their chances of survival. This is encapsulated by the following quotation:

'I said if you think you're gonna have to take the breast off then just do it. I said just get rid of it all and then I'll be alright' (Fiona).

For one participant, this strive for survival was grounded in past experiences of cancer resulting in death.

'All I've known is people dying from cancer and so I said take it off, as it turns out they said I could have had a lumpectomy but I couldn't take the chance' (Jenny).

Removing the breast was also seen as a means of returning to 'normality' quicker as some women associated a lumpectomy with requiring further treatments such as chemotherapy.

'I've no chemotherapy, no radiotherapy, nothing because they've taken everything away' (Linda).

One participant described her initial reaction as wanting both breasts to be removed though had been advised against this by the Consultant. While her

primary motive was also one of survival, she was one of the youngest women in this sample and her prime motivation was to see her children grow up. Subsequently, when reflecting on the treatment decision-making process the participant acknowledged that a mastectomy would have been a drastic move.

'Initially, my reaction was just to get it taken off altogether, well both actually and I really wanted that . . . I really did. I've had my kids and I'm living my life and I just wanted to get rid of them both. I don't think it was a mental thing I was going through I just thought that was the best thing and then it'll never come back but the Consultant said that was far too drastic, it wasn't to that degree. She told me for a reason that I only needed a lumpectomy  
. . . so you do what they say don't you, you do what they think is right'  
(Laura).

Acceptance of and trust in medical opinions was therefore crucial in influencing the final surgical decision made. Deciding to take a passive role was however done so consciously and stemmed from the desire to have assurance that cancer has been eradicated and normality could return. Despite facing months of treatment, Rose also perceived 'getting rid of it' as facilitating this return to normal.

'I feel as though that's it, it's gone now, it's a case of just getting on with my life, getting sorted, so I can't wait for the chemo to end and then I can get back to normal'.

Once surgical intervention had been undertaken and the problem had been 'removed' women reported no longer having breast cancer.

'I believe at this moment in time I haven't got breast cancer in me. I think they got all of it out with the surgery and the treatments that have followed are just to make sure it doesn't come back' (Susan).

This suggests that once women no longer believed they had cancer deciding on subsequent treatments was not perceived in the same way as for surgical decision making. This is perhaps reflected in the greater passivity adopted following surgery. Women's beliefs about cancer and the impact of these on treatment decision making are discussed further in the following theme.

#### ***Theme 4: Cancer schema***

All women were found to hold a set of beliefs about what constitutes having breast cancer (or not), in other words, their cancer schema. Such schemas were modified throughout women's experiences of treatment decision making with the acquisition of new knowledge. All participants described being given information about breast cancer and treatment options at the time of diagnosis. In particular, they described receiving in-depth explanations by the medical team about surgical options as well as receiving an information pack, which they could take home. However, women's ability to process this information and to utilize this as part of the treatment decision-making process was found to be limited by their cancer schemas.

'I think it was watching him that made me realise what she'd said because I heard the word and I can honestly say I don't think I heard another word after that' (Laura).

Many women associated cancer with death and as a result found the information provided anxiety provoking.

'They gave me some books about breast cancer and I started to read them that day but then I think there's only so much you can face and so I put it to one side' (Mary).

Similarly, Jenny commented:

'I've read through it but I don't like reading it because it just reminds you of what you've been through and what you've had. I think I've read through it once and then my son has had a look at it . . . I did read in there that you can get it in the other breast and I think that's put me off reading any more'.

Setting aside the written information received was common among this sample particularly until after surgical intervention had been completed and all treatment decisions had been made. Several women reported giving their information pack to a relative to be reviewed if a specific question arose, typically regarding treatment side effects.

'My mam has the breast pack of mine and I say to her will you have a look to see if there's anything in there about your mouth ulcers whereas if I had the book in front of me I'd be thinking well I didn't have that but I've got it now. If you read it you get into your head that you've got it' (Emma).

Television programmes and books depicting others' experiences of cancer were also actively avoided by many participants during the first few months post diagnosis and for some this avoidance persisted throughout the data-collection period. That said, once the treatment decision-making process had been completed over half of the participants in this sample made the conscious decision to seek information using the Internet. This was particularly evident for women undergoing a long period of treatment as well as for women deciding whether to proceed with reconstructive surgery.

'I'm terrible, I need to know down to every little thing. At the minute I'm researching all about reconstruction, all the different types of things you can have, what they do. So when I go I'll just say I don't need to come back to decide because I already know' (Gillian).

Such information seeking facilitated women, like Gillian, to gain control over their experience and take an active role in further treatment decisions.

### ***Discussion***

The findings from these four themes illustrate the similarities and diversity among women's experiences of breast cancer treatment decision making.

The first key finding to be considered is that many of the participants preferred to adopt a passive role in surgical treatment decision making. While given the qualitative nature of the present study comparisons to quantitative research is limited, this finding does contrast that of previous research that reports that only 8% (Lam, Fielding, Chan, Chow, and Ho, 2003) and 13% (Janz *et al.*, 2004) of women with newly diagnosed breast cancer prefer this level of involvement. Other studies (e.g., Degner *et al.*, 1997; Vogel *et al.*, 2008) have reported higher rates of passivity (34% and 40%, respectively) in the treatment decision-making process though these were not specific to surgical decisions. Cultural differences and differing healthcare systems as well as variation in study samples and methods utilized could account for such conflicting results.

Importantly, this study has found that women's actual level of involvement, including those adopting a passive role, in surgical treatment decisions was in accordance with their individual preferences. This finding is in contrast to previous research suggesting that over half of women with breast cancer do not achieve their desired level of involvement in surgical decision making (Degner *et al.*, 1997). Breast cancer patients who feel a lack of concordance between desired and actual levels of involvement are more likely to report decisional regret (Lantz *et al.*, 2005). Thus, it is perhaps not surprising that women in this study did not describe experiencing this at any point in the year following

diagnosis. Moreover, women rarely made reference to other treatment options throughout the data-collection period and when doing so only commented on the negatives of alternative surgical options. This process can be explained through Festinger's (1957) Theory of Cognitive-Dissonance since either dissonance was not experienced over time because the women were satisfied with the treatment option all along, or women avoided reflecting more in depth on the treatment decision in order to avoid the uncomfortable feeling of dissonance. Their lack of interest in reading the information provided and any other breast cancer related texts as revealed by the women at all stages of the longitudinal enquiry; seems to support the latter explanation of remaining positive in order to avoid cognitive dissonance.

Furthermore, the accounts provided by women throughout this research suggest that decision-making role can vary between surgical and non-surgical treatment decisions. Specifically, none of the women interviewed described any involvement in selecting additional treatments (e.g., chemotherapy, radiotherapy, or drug therapies) citing the multidisciplinary team as the 'decision-makers'. Women accepted these decisions, often due to experiencing shock at the diagnosis they had been given and as a result felt unable to make life-altering decisions. The model of emotional trade-off difficulty in decision making (Luce, 2005) provides some insight into such findings. Based on coping literature, specifically that of Lazarus and Folkman (1984), the model suggests that women may be influenced by their need to cope with the difficult trade-offs (e.g., long-term survival vs. breast loss) that characterize treatment decision making for breast cancer. In an attempt to minimize the emotional impact, a desire to avoid considering such trade-off's irrespective of the information available, may be generated. As such having autonomy over decisions, particularly when positive outcomes cannot be guaranteed, may increase patient stress and as a result handing over control to medical professionals may be a positive coping strategy. Moreover, in making problematic trade-off's implicit, the decision maker does not directly confront the advantages of other options further minimizing potential stress.

For many women participation in non-surgical decisions was not deemed to be an option. This finding supports those by Kreling, Figueiredo, Sheppard, and Mandelblatt (2006) who in a qualitative study exploring factors associated with chemotherapy use in older women with breast cancer found that the majority of women did not feel that they had a choice though that many preferred this style of decision making. The visible impact of surgical intervention on a woman's body may be one potential explanation for women reporting differing levels of surgical and non-surgical decision making. The strong desire by women in this study to 'get rid of it' via surgery may indicate

that non-surgical interventions are viewed as less tangible, that is, their effects on the body and on breast cancer are less evident.

This study has further found that women adopting a passive role (in either surgical and/or non-surgical decisions) were not disengaged from the decision-making process and as previously identified by Seale (2005), this role was chosen consciously. However, unlike previous qualitative research (e.g., Halkett *et al.*, 2007) the present study further suggests that such passivity was deemed to be a positive aspect of women's experience and that control was not perceived to be lost but rather that ownership of decisions was maintained throughout the process. It must not be forgotten that several women in this research did perceive themselves to have had an active or collaborative surgical decision-making role. That said, these women did report discussing treatment decisions with their Consultant and thus a model of shared decision making (e.g., Charles, Gafni, and Whelan, 1999) is more applicable. Nevertheless, all women were subsequently passive in relation to additional treatment decisions and were satisfied with this course of action.

However, the recently published Government White Paper for Health (Department of Health, 2010) has the principle of 'shared decision-making' at its core. It advocates 'involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone' (p. 13). While research indicates that patient involvement in decision making may result in better long-term health outcomes (e.g., Anderson, Bowen, Morea, Stein, & Baker, 2009) and increased compliance with medical regimes (e.g., Cameron, 1996) some breast cancer patients do not desire this level of involvement and those doing so may engender specific characteristics, for example, a family history or a recurrence.

An acceptance of and trust in the medical professionals involved in their care was the underlying reason for women in this sample not having greater decisional involvement. Throughout the data-collection period, women continually made reference to the confidence they had in the abilities and experience of the surgeon, breast care nurses, and all other team members. Similar findings have been reported recently by Mendick, Young, Holcombe, and Salmon (2010) who observed consultations and explored the perspectives of women with breast cancer and their doctors on treatment decisions. The study reported that while surgeons made the majority of decisions, women did not feel the need to question this given their trust in the surgeon's expertise. Such findings complement those of previous quantitative investigations (e.g., Temple *et al.*, 2006), which have found that factors such as doctor's advice and hopes of being cured were fundamental in the treatment decision-making



process.

The strive to be cancer free was another key finding of the present study and was one which influenced women's decision making. A small number of participants requested a mastectomy due to either recurrence of their own tumour or through previous family experiences. Underlying these decisions was a need to increase their chances of survival. This was particularly important for younger participants who had school-aged children.

For some women, a mastectomy was viewed as a means to eradicate breast cancer and as a result returning to 'normality' quicker. From a longitudinal perspective, this study has found that from the completion of surgery women state that they no longer have breast cancer. This belief indirectly influenced additional treatment decision making as well as the management of breast cancer information.

While not measured during this study, it is noteworthy that many women's knowledge of the benefits and disadvantages of different surgical and other treatment options was found to be limited. However, the research reported here does identify reasons for this, one being that women's existing cancer schemas limited the amount of information processing that was possible at the time of diagnosis. Secondly, for some women reading the materials provided by the breast unit proved to be too anxiety provoking and active avoidance of cancer related information was common, particularly during the early stages of their experience. Managing information to avoid becoming overwhelmed and information increasing fears were reported in a recent study by Lally (2009). It is also plausible that as women trusted the healthcare professionals involved in their care so implicitly that it was not deemed to be necessary to engage in further information- and explanation-seeking behaviour, particularly given the anxiety that occurred as a result.

The longitudinal nature of this research has enabled in-depth exploration of issues relevant to women's experiences of breast cancer throughout the year following diagnosis.

### ***Limitations***

The nature of conducting qualitative research means that this work reflects the experiences of the individuals in the sample recruited for this study. In addition, qualitative data analysis requires interpretation on the part of the researcher though member checking was undertaken with all participants after each interview was analysed in order to ensure the accuracy of the findings.

Twenty women participated in this longitudinal qualitative study, which has facilitated the collection of in-depth information about the meaning of

women's experiences of treatment decision making. However, the size of this sample and the difficulty obtaining an accurate response rate limits the extent to which the results can be generalized.

The self-selecting nature of the sample also needs to be addressed. Attending a symptomatic breast care unit with a suspicious breast lump is in itself a highly stressful and anxiety-provoking experience for any woman. To have attempted to recruit participants at this distressing time would have been unethical and an intrusion into the lives of these women. The method of recruitment used was deemed to be the least intrusive and depended (to a certain extent) on the altruism of each participant to respond to the research materials provided and agree to participate in the study. As such, the decision-making experiences of other women (who did not participate) may have been missed, as given ethical constraints, it was not possible to collect data on those women who did not choose to participate.

### ***Future directions***

Despite the extensive body of literature about breast cancer and decision making, there remains many areas requiring further exploration in order to build upon our understandings of women's experiences of treatment decision making in breast cancer. The current study also suggests that research investigating women's responses to information and explanation particularly during the immediate post-diagnosis phase is essential if we are to further understand women's experiences of breast cancer.

The present study also identified that a history of non-malignant breast disease and the loss of loved ones to cancer were influential in surgical treatment decision making. However, such factors have been largely neglected in the literature. Similarly, women's experiences of decision making for non-surgical interventions, in particular radiotherapy, Herceptin and Tamoxifen, require further exploration. Finally, in-depth analysis of how women's experiences of treatment decision making is reflected in the avoidance of cognitive dissonance and how this influences coping with their illness and impact upon future decision making would be beneficial in order to better care for women given a diagnosis of breast cancer.

### ***Case study: Laura***

Laura identified a lump in her breast while at home however decided to wait several weeks before seeking medical attention via her GP. On attending the breast clinic, a mammogram and biopsy were performed and Laura returned to

the clinic the following week to receive the diagnosis of breast cancer. Her immediate response of disbelief turned to shock upon seeing her husband's reaction to the news. The lack of symptoms experienced that Laura perceived to be associated with breast cancer as well as having a cancer schema linked to mortality were described as underpinning these emotional states. After initially requesting a bilateral mastectomy in order to maximize her chances of survival, for the sake of her young children, Laura decided to follow the advice of the medical professionals involved in her care. As such Laura underwent a lumpectomy followed by chemotherapy and radiotherapy and was prescribed Tamoxifen for 5 years. When asked about the treatment decisions made Laura repeatedly discussed having trust and confidence in the knowledge and experience of the medical staff. She stated that although decisions were made by the medical team and that consequently she was not in control of the treatments offered to her, handing over control was performed consciously and willingly. Furthermore, upon reflection Laura commented that her initial reaction regarding surgical intervention was 'too drastic' and felt that the emotions being experienced at the time of diagnosis contributed to this response. While Laura did refer to the medical information booklets provided at the time of diagnosis, this was typically only looked at when searching for a treatment side effect. Being able to contact the breast care nurses by telephone for advice at any time was viewed by Laura as more reassuring than any written information, whether medical or otherwise, available to her.

### ***Conclusions***

Through a longitudinal qualitative exploration, this study has found that while many women adopt a passive role in treatment decision making doing so was viewed as a positive aspect of their experience. Furthermore, women felt in control of the decision-making process and did not report experiencing decisional regret at any point throughout the year following diagnosis. Women's implicit trust in the healthcare professionals and an overwhelming desire to 'get rid' of breast cancer also influenced decision making. However, avoidance of medical information was common and women continued to manage information-seeking post diagnosis. Further psycho-social exploration of interactions during consultation is needed to identify how to support women throughout this process and beyond.

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## APPENDIX 10

## **Summary of findings**

Waiting was found to be a central aspect of the experiences of those women interviewed for this study, which has illustrated the prevailing nature of waiting in the context of breast cancer from help-seeking to the diagnostic process and treatment commencement. Novel findings were reported in relation to treatment decision-making, particularly regarding non-surgical interventions, an area lacking qualitative exploration in the UK. The passivity reported, including via deferring to the expertise of the multi-disciplinary team, was not found to denote a loss of control but accepting medical opinions was perceived to be a means of maximising the chances of survival through 'getting rid of it'. Having ultimate control over whether to undergo treatment further enabled participants to maintain ownership of the decisions made. In addition, women rationalised surgical decisions through contemplating the meaning, and often the lack of importance, of their breasts, a finding which is again unique to this research. The shock elicited by the diagnosis of breast cancer was perceived to hinder some women's involvement in treatment decision-making yet by choosing passivity they avoided additional anxiety. Medical information was also perceived to be anxiety-provoking and revealing women's long-term information management (e.g. through avoidance) adds to the existing literature in this field.

While denial featured in a minority of women's accounts this was short-lived and women typically accepted their diagnosis and prescribed treatment regime and began to engage coping strategies to manage ongoing treatment and the physical and psychological impact of their experience. Immediately post-surgery, and regardless of the type of surgery conducted, women began to experience a negative impact on their body image, one which extended throughout the study timeframe. Breast loss did, nevertheless, elicit specific



issues regarding body shape and symmetry as well as grief for the missing breast(s). External breast prostheses, delayed reconstruction, and careful clothing selections were strategies used to normalise appearances for the protection of the self and others.

The women interviewed reported experiencing a wait for normality which for many women was described throughout the data collection period though was particularly evident during hospital-based treatments as women waited for a return to a life without treatment regimes, physical limitations and psychological disorientation. The physical limitations stemming from surgery and adjuvant treatments resulted in women experiencing a loss of a healthy and feminine identity as their roles within the home were undertaken by loved ones causing conflict and upset. Treatment side-effects were further perceived to denote signs of illness with chemotherapy associated alopecia being perceived to be the most indicative of being treated for cancer leading participants to disguise hair loss to avoid perceived stigma. This research contributes to current knowledge of women's longitudinal experiences of treatment side-effects including the under-researched areas of radiotherapy and Tamoxifen as well as women's perceptions of utilising alternative therapies to manage side-effects and improve psychological well-being.

The present study addresses the paucity of longitudinal qualitative research exploring women's psychological responses to breast cancer over time. Diagnosis led to reflection on existential concerns with women contemplating mortality and 'why me?' which often preceded an episode of psychosocial distress including reactive depression and disorientation. This study has uncovered that for women undergoing additional adjuvant therapies this coincided with the aforementioned issues pertaining to illness identity and (for

all women) coping with bodily changes. Nonetheless, despite the disruption to women's lives they adopted positive cognitive restructuring and benefit finding to cope throughout their experience which resulted in participants re-defining their priorities and reforming their relationships with others. Women demonstrated variability in taking responsibility for their breast health though did initiate more general health related behaviour change through adaptations to diet and physical activity. However, breast cancer remained at the back of women's minds with an ongoing uncertainty about their future permeating their thoughts, reinforced by changes to the body and ongoing treatment regimes (e.g. Tamoxifen).